

The educational impact of being a young carer aged 16 – 24 in Northern Ireland

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Abstract

Very little is known about young carers in Northern Ireland generally and much less about their experiences of education. The aim of this thesis is to provide an insight into the educational impact of being a young carer (aged 16-24) in Northern Ireland. Prior knowledge on young carers in Northern Ireland has been limited to census figures, social survey data (the Young Life and Times Survey) and a report commissioned by the Patient Client Council - data that has not previously been collated together.

A mixed methods approach was adopted, and data was collected from young carers aged 16-24, and professionals working with them. The research design focused on establishing the educational experiences of young carers, the relationship between their caring role and education, the support they received and how they could be supported to achieve their academic potential. A survey of young carers across NI was undertaken and this provided 35 responses. In addition to this, semi-structured interviews were carried out with 6 young carers and 13 professionals. Data was analysed using NVIVO and SPSS. The research also provided secondary analysis of the cross-sectional data available on young carers in Northern Ireland through the collation of Census figures and the Young Life and Times Surveys.

Research findings emphasise the uniqueness of each young carers experience both in their caring role and within education. It identifies young carers as having a positive attitude towards education, the importance of having a certain mindset and as viewing their places of education as a break from providing care. However, almost two-thirds agreed that their grades had been negatively impacted by their caring role. Their caring role also impacted on their education in other ways including homework completion, concentration and making decisions about their future choices. Although sources of support were identified, approximately half of young carers felt unsupported by their teachers who, they believed, did not understand their caring role. Professionals highlighted the difficulties they had experienced building relationships with schools.

The original contribution of this research is primarily that it provides additional information and new insights about the experiences of young carers in Northern Ireland and their education.

List of Acronyms

ARK	Access Research Knowledge
CYPSP	The Children and Young People's Strategic Partnership
DE	Department of Education
DEL	Department of Employment and Learning
DfE	Department for Economy
DHSSPS	Department of Health, Social Services and Public Safety
EA	Education Authority
EMA	Education Maintenance Allowance
ESA	Education Skills Authority
EWO	Education Welfare Officer
GB	Great Britain
HSCB	Health and Social Care Board
HSSBs	Health and Social Services Board's
NCB	The National Children's Bureau, Northern Ireland
NEET	Not in Education Employment or Training
NICCY	Northern Ireland Commissioner for Children and Young People
OFMDFM	Office of the First Minister and Deputy First Minister
PCC	Patient Client Council

SENCO	Special Educational Needs Co-Ordinator
UK	United Kingdom
UNCRC	The United Nations Convention on the Rights of the Child
UNOCINI	Understanding the Needs of Children in Northern Ireland
YLTS	The Young Life and Times Survey

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1.0 Introduction

1.1 Background

A young carer is a child or young person under the age of 24, whose life is affected by providing significant care, assistance or support to sick or disabled relatives at home. The term young adult carer is used specifically for young carers aged 18-24 (Sempik and Becker, 2013a; Sempik and Becker, 2013b; Northern Ireland Department of Health, Social Services and, Public Safety, 2006; Dearden and Becker, 2000).

To date, research on young carers in Northern Ireland has been limited to Census figures and social survey data (the Young Life and Times Survey). Little is therefore known about young carers in general in Northern Ireland and even less about the impact of their caring role upon their education. This contrasts to Great Britain (GB) where studies on young carers have been carried out by various researchers, for example Becker and Becker (2008) and Sempik and Becker (2013a; 2013b).

The absence of research on young carers in Northern Ireland means that there is a knowledge gap and therefore policy is not formulated on evidence. This lack of research has the potential consequence that the need for young carer specific policies may not be fully realised or even identified. It cannot be assumed that the findings of GB studies (which do not include NI participants) are representative of the experiences of young carers in Northern Ireland. Northern Ireland is distinctive compared to the rest of GB as it is a post conflict society, and this has been documented as having an impact on the instances of disability in NI and child poverty. A 2014 report identified that a fifth of children in Northern Ireland lived “with an adult who had ‘high experience’ of the conflict” (Child Poverty Alliance, 2014, p.vi). This is of significance to young people with a caring role in two ways, firstly those living with someone with “‘high experience’” of the conflict are identified as “significantly more deprived than those with no conflict experience” (Ibid). Secondly, children who live with a disabled parent or sibling were recognised as “most likely to experience poverty” (Ibid).

This research focuses specifically on the educational impact of being a young carer in Northern Ireland, an area not focused on before. It was influenced by the work of Becker and Becker (2008) and Sempik *and* Becker (2013a; 2013b) who researched young carers and their education in England, Scotland and Wales aged 16 to 24 and in doing so set out a blue print of important issues and factors to consider for a NI-based study.

The work of Becker and Becker (2008a), (a mixed methods study that involved 25 young carers project's and 13 adult carer services), highlighted that this role was impacting on a young carer's education, career options and economic potential. Young carers involved in their research reported on leaving education that their qualifications were not of the standard that they could achieve.

Sempik and Becker's (2013a) report reinforced such findings with over half of respondents in their research believing they would have done better at school had it not been for their caring responsibilities. Significantly, this report concluded that for those young carers not in employment, it was because they did not have the educational qualifications to gain employment. It was also reported that when it came to gaining qualifications, young adult carers found it more difficult to progress through higher education especially when there is the assumption that they will continue in their caring role. Further research by Sempik and Becker (2013b) provided some insight as to why this may potentially be the case. They elaborated that poor educational outcomes could be explained by young carers having problems attending their place of education and they emphasised the emotional impact and worry involved in caring for someone. Sempik and Becker (2013a; 2013b) from the University of Nottingham were commissioned by the Carers Trust to "examine the experiences and aspirations of young adult carers with regards to school, further and higher education, and work" (p.2). This research used an online survey of young adult carers and had 295 respondents).

1.2 Research aim and objectives

The overall aim of this research was to produce, for the first-time, insights on the educational impact of being a young carer (aged 16-24) in Northern Ireland. To address this aim, the following questions will be focused upon:

1. What are the educational experiences of young carers aged 16-24 in Northern Ireland?
2. How has the caring role impacted on their experience of education and/or career prospects?
3. What help did young carers receive to support them in their education and how can they be supported to fulfil their educational potential?
4. How does the educational experience of being a young carer in NI compare with Great Britain (GB) and elsewhere?

1.3 Rationale for the research

To date, there has been limited empirical evidence on young carers (Champlain, 2012, p.38; Newman, 2002, p.613; Lackey and Gates, 2001). Newman (2002) argues that there is little measurable evidence for claims about young carers that “have no direct relationship to illness or impairment” (p.613). Specifically, in relation to assessing academic performance and school attendance, measurable evidence has not been readily collected (Champlain, 2012; Lackey and Gates, 2001). It has also been identified that more research is required on young people’s perspective of their caring role and their parent’s health and wellbeing as it is “an aspect that is missing” (Mechling, 2011, p.33).

Very little is known about young carers in Northern Ireland and even less about the impact of a caring role upon their education. Research thus far has been limited to Census figures, social survey data (the Young Life and Times Survey) and a subsequent report commissioned by the Patient Client Council in 2010. This study will include the aggregation, collation and secondary analysis of this

cross-sectional data on young carers in Northern Ireland as it seeks to explore the experiences of young carers in education in Northern Ireland aged 16 to 24 years old. By focusing on this age profile, it is anticipated a deeper insight into the experiences of young carers and their education in Northern Ireland can be gained. This age is a time of transition for young people: some will leave school at sixteen, others will move to a regional college, complete A-Level qualifications, go to university, other training or employment. Alternatively, some may choose none of these options. This study will provide a more detailed understanding of young carers in Northern Ireland and, in doing so, act as a potential reference source for policy makers, education providers and young carers' organisations.

1.4 Motivation for the research

This project was motivated by the Researcher's seven years professional experience working with young carers aged five to twenty-three in a voluntary organisation in NI that supports young carers. Through this professional role it became clear that young people with caring responsibilities were experiencing problems with their education (in various forms) at GCSE and A- Level and there was increasingly a need to advocate to places of education on their behalf. It was also apparent when applying to funding bodies to dedicate more resources to this issue, there was little Northern Ireland research evidence to cite to underpin the case for increased funding. See also Section 4.11 of the thesis which considers reflexivity, the role of the researcher in the research process and any implications for this study.

1.5 Theoretical approach

This research will be rooted within Bronfenbrenner's (1979) Socio Ecological Theory. The theory describes social environment as "a nested arrangement of structures" placing the individual at the centre surrounded by four successive levels- the micro-system, the meso- system, the exo-system and the macro-system (Bronfenbrenner,1976, p.5). Bronfenbrenner describes a person's development in a social environment as "a function of forces emanating from multiple settings and from the relations between these

settings”, with each environmental level impacting differently on the development of each individual (1999, p.17). It therefore provides a theory-based framework through which to understand the complex, shared outcomes of personal and environmental factors (Kilanowski, 2017). Figure 1 offers a visual representation of the levels.

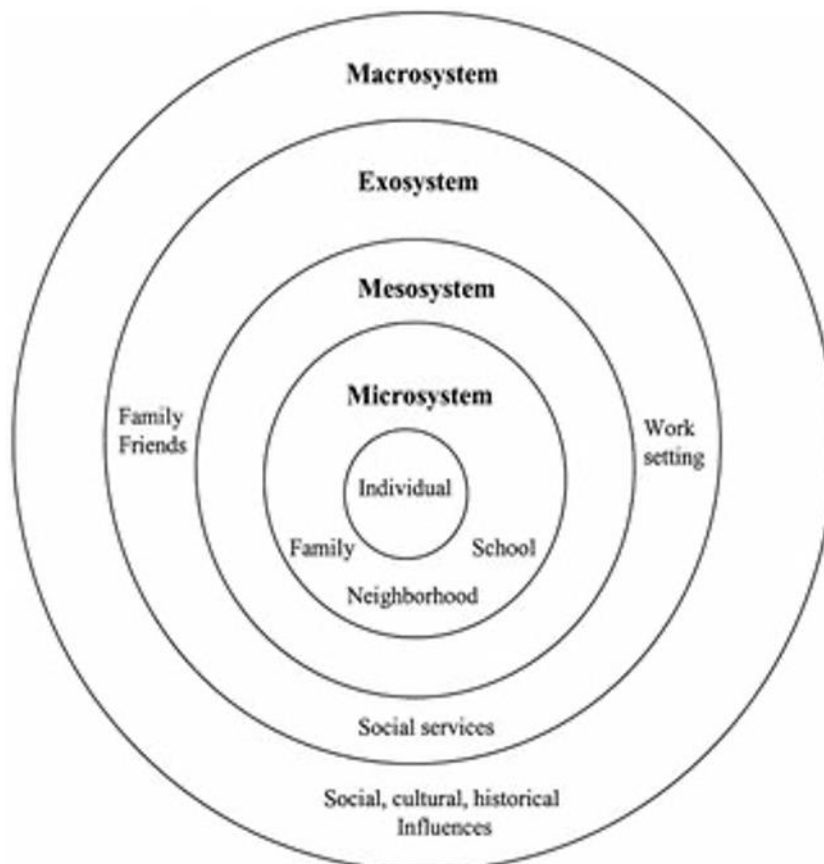


Figure 1: Bronfenbrenner's Ecological Systems Model (Adapted from Bronfenbrenner, 1976, pp.5-6)

The *micro-system*, or *Level One*, refers to the immediate environment of an individual. This level is defined as a place in which “occupants engage in particular activities in particular roles...for particular periods of time”, including interpersonal relationships (Bronfenbrenner, 1976, p.5). Examples include home, school and the neighbourhood in which they live.

The *meso-system*, or *Level Two*, is the “system of the micro-systems”, the interconnectedness or interrelations among the systems containing the individual (Bronfenbrenner, 1976, p.6). An example of this would be “the relationship between family experiences and school experiences” (Onwuegbuzie, 2013, p.4).

The *exo-system* representing *Level Three*, is an “extension of the meso-system” and includes formal and informal social structures (Bronfenbrenner, 1976, p.6). It refers to “one or more settings that do not involve the developing person as an active participant, but in which events occur that affect or are affected by, what happens in the setting containing the developing person” (Bronfenbrenner, 1979, p.25). Such settings include local, state, national governments and their agencies, communication and media, working environment, neighbourhoods where people live, the distribution of goods and services and informal social networks.

Level Four, or the *macro-system*, refers to the “overarching institutions of the culture or sub culture, such as economic, social, educational, legal and political systems, of which local micro-, meso-, and exo-systems are the concrete manifestations” (Bronfenbrenner, 1976, p.6). These are to be seen “not only in structural terms but as carriers of information and ideology” and whether explicit or implicit this gives “meaning and motivation to particular agencies, social networks, roles, activities, and their interrelations” (Ibid). In other words, it includes laws and policies that indirectly impact on the individual, ideologies, cultural norms and societies belief systems (Onwuegbuzie, 2013).

Due to its construct Bronfenbrenner’s ecological systems theory is a useful model for social sciences research. It has particular relevance when exploring young carers’ experience of education for three main reasons. Firstly, young carers experience significant interaction between, and impact from, the four levels of the model, arguably more so than many of their peers. Secondly, previous research and peer reviewed literature has highlighted their experience within and across these levels can impact upon their education (See Chapter 3.0). For example, a lack of respite support for the person the young person is providing care to and the possible economic disadvantage of this same family may limit access to education (Hamilton and Adamson, 2013; Heyman and Heyman, 2013; Family Action, 2012; Pakenham and Bursnall, 2006; Moore, 2005). Thirdly, the interconnected nature of the four levels reflects the qualitative and quantitative elements of this research project work which align to examine “the same phenomenon at the same or different levels” (Onwuegbuzie et al., 2013, p.6).

1.6 Outline of the thesis

Chapter One, is an introduction to the research project, it outlines background to the study, the research aims and objectives, the rationale for the study, the theoretical approach engaged and provides an outline of the thesis.

Chapter Two, sets the scene regarding what is already known about young carers in Northern Ireland. It will present NI Census figures and results from Young Life and Times Surveys. Policy, strategy and legislation will then be examined, focusing on those relating to carers, education, children and young people, health and well-being, child poverty and any other NI reports relating to young carers, children or young people.

Chapter Three is a review of the peer and non- peer reviewed literature retrieved through applying a systematic literature review methodology.

Chapter Four will focus on the research methodology. It will outline the mixed methods approach employed as well as presenting the inclusion criteria and sampling approach used, how participants were accessed, and an overview of the young carers' organisations being engaged with. It will also explain the survey and interview designs and implementation, the data analysis process used, address ethical considerations and reflexivity and evaluate the research design.

Chapter Five will outline findings from surveys and interviews with young carers and interviews with professionals.

Chapter Six will be a discussion of the research findings presented in chapter five.

Chapter Seven provides the conclusion to the thesis, including recommendations to help support young carers in education and identifying potential areas for future study.

2.0 Setting the scene

2.1 Introduction

This chapter will introduce and discuss what is known about young carers aged 16 to 24 in Northern Ireland. Quantitative and qualitative research on young carers has been limited in Northern Ireland, to date. Quantitative research has been largely limited to Census figures and the results of Young Life and Times survey's undertaken by ARK¹, whilst qualitative data has generally been in the form of commissioned research. Northern Ireland-specific policy and legislation and how this relates to a young person with a caring role will also be outlined. Other research may have presented discrete findings from pre-existing quantitative data on young carers in Northern Ireland, however, this research aggregates and collates all existing cross-sectional data on young carers from Census figures and Young Life and Times Survey's in Northern Ireland. Such secondary analysis provides a value-added perspective allowing for prior trends to be identified and enabling the triangulation of research findings.

2.2 Northern Ireland Census Figures

Prior to 2001, the NI Census did not include any questions relating to the provision of unpaid care for family, friends or others. The following question was included in both the 2001 and the 2011 censuses:

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

¹ <https://www.ark.ac.uk/ARK/> ARK (Access Research Knowledge) is a social policy hub whose work includes public attitudes surveys that record the views of adults, children and young people living in Northern Ireland about the issues that affect their lives.

Respondents were explicitly instructed not to “count anything you do as part of your paid employment”². The results were disaggregated to represent the age, sex and general health of respondents³. Table 1 shows a breakdown of data specific to the young carer population.

Table 1: Census results 2001 and 2011 regarding young carers in Northern Ireland

	<i>2001 Census</i>	<i>2011 Census</i>
<i>Numbers of young carers identified aged 16-24</i>	13,419	16,171
<i>% of population aged 16-24 identifying as a young carer</i>	6.4	7.3
<i>% of young carers female</i>	58.6	55.2
<i>% of young carers male</i>	41.4	44.8
<i>Most common number of hours young carers providing care</i>	1-19	1-19

A higher proportion of young carers were identified in Census 2011, representing an increase of 2,752 (over 20%) from Census 2001; by association, the percentage of the population aged 16-24 identifying as young carers increased from 6.4% in 2001 to 7.3% in 2011. Although the proportion of young female carers decreased slightly between 2001 and 2011, the proportion of young male carers increased rising from 41.4% to 44.8%.

Census figures depend on parents reporting their children provide care at home; as this data is based on “self-reporting” it is possible that figures underrepresent overall numbers, particularly those caring for someone with a mental health

² <http://www.nisra.gov.uk/archive/census/2011/forms/household.pdf>,
<http://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2001-census-household-questionnaire.pdf>.

³ <http://www.nisra.gov.uk>

problem or with drug and/or alcohol dependency (Becker, 2007). In these instances, many parents do not always recognise their child/children's help as caring, assuming that it will be done out of instinct, love and/or duty. Many young carers, therefore, may not be routinely identified and often do not label themselves as such (Becker and Becker, 2008).

The 2021 Census for Northern Ireland proposal document has included the topic and questions on the provision of unpaid care⁴.

2.3 Northern Ireland Young Life and Times Survey and Young Carers

The Young Life and Times Survey (YLTS) is an annual survey undertaken in NI by ARK to ascertain the views of young people in response to a range of topics relevant to their lives⁵. This is administered to a random sample of young people aged 16 years old taken from the Child Benefit Register, provided to ARK by Her Majesty's Revenue and Customs. Questions on particular topics are presented within individual modules, some modules are funded by government departments and some are funded by individual agencies or research groups. Prior to 2010, limited questions were asked about young people and their caring role. Since then, there have been regular but intermittent modules on young carers and the focus of these have changed over the years, influenced, in part, by the funding source for the module.

⁴ <http://www.nisra.gov.uk>

⁵ <http://www.ark.ac.uk/yлт/about>.

2.3.1 The Young Life and Times Survey 1998-2009

The YLT surveys in 1998, 1999 and 2000 each contained two questions on young people's caring role for someone who is "sick, handicapped or elderly"⁶. One question focused on care given to a person they lived with and the other on care given to a person not living with them. Table 2 provides a summary of the numbers and percentages of responses. No gender breakdown was provided.

There was no YLTS in 2001 and 2002 and questions on caring were not included in YLTS between 2003-2005. In YLTS 2006, the same two questions administered in previous surveys were repeated with a gender breakdown provided for the first time.

In YLTS 2007, in addition to existing questions, young people were asked who they looked after and the caring tasks they carried out, which covered a wide spectrum of activities⁷. Amongst those young people living with the person they cared for, over half helped a parent with housework or provided general care for a grandparent (25 respondents). Other respondents cared for a sick or disabled sibling (6 respondents), helped with the childcare of siblings (5 respondents), supported or gave general care to a sick or disabled parent (5 respondents), helped siblings with schoolwork (2 respondents), gave general care to an aunt or provided other care (5 respondents). Young people often performed more than one caring task. Amongst those providing care to someone not living with them, over half helped a grandparent or other relative with their housework or garden (42 respondents). Others provided general or social care for a grandparent or other relative (11 respondents), helped a family friend or neighbour (6 respondents), provided babysitting (4 respondents), helped in a relative's business (2 respondents), volunteered to help someone elderly (3 respondents) or provided other care tasks (10 respondents)⁸. The data similarly indicated that young people often performed more than one caring task.

⁶ <http://www.ark.ac.uk/ylt/1998/ylt98.PDF>; <http://www.ark.ac.uk/ylt/1999/ylt99.PDF>; <http://www.ark.ac.uk/ylt/2000/ylt00.PDF>.

⁷ <http://www.ark.ac.uk/ylt/2007/Family/>

⁸ The number of respondents to the question was too small to calculate a percentage.

In 2008 and 2009, the YLTS asked young people the same questions included in 1998, 1999 and 2000 which asked if they provided care for someone they live with or someone they do not live with⁹.

Table 2: YLTS Numbers and proportions of young people with caring role 1998-2009

	1998 YL&T (N= 356)	1999 YL&T (N= 449)	2000 YL&T (N= 259)	2006 YL&T (N= 770)	2007 YL&T (N= 627)	2008 YL&T (N= 941)	2009 YL&T (N= 857)	Mean 1998- 2009
<i>Percentage providing care for someone they live with</i>	7% N=25	7% N=31	9% N=23	9% N=69	9% N=56	9% N=85	7% N=60	8% N=49
<i>Percentage providing care for someone not living with them</i>	15% N=53	9% N=40	6% N=16	24% N=185	14% N=88	19% N=179	18% N=155	15% N=102

By YLTS 2006, the number of respondents had more than doubled, there was a peak in 2008 of those young carers providing care to someone they lived with and a significant rise over this period in the proportion of young people reporting that they provided care for someone not living with them. Between YLTS 1998 and 2009 the proportion of young people providing care for someone they lived with varied within a two percent range; however, during this same period the proportion of young people providing care for someone not living with them had a greater level of variance (18%).

⁹ <http://www.ark.ac.uk/ylt/2008/YLT08quest.pdf>;
<http://www.ark.ac.uk/ylt/2009/YLTquest2009.pdf>.

2.3.2 The Young Life and Times Survey 2010

In 2010, the Patient Client Council (PCC) in Northern Ireland funded a module on young carers ¹⁰. The results provided the most comprehensive details to date about young carers in Northern Ireland as it contained further questions for those with a caring role asking; if the person they cared for lived with them or not, who they were providing care to, how many hours and days a week, length of time they have been providing care, the tasks they carry out, whether they had told someone outside their family about their caring role, whether or not they and their family felt their caring role was private and should not be spoken about outside the family, who also supported their cared for person, as well as providing statements for young carers to respond to¹¹. The data indicated that:

- Seventy-one (9.0%) out of the seven hundred and eighty-six respondents reported having caring responsibilities, comprising slightly more females (n=39; 5.0%) than males (n=31; 4.0%).
- Of this number, thirty-seven respondents provided care for someone they lived with and thirty-eight provided care for someone they did not live with.

It should be noted that the distinction between a young person living or not living with the cared for person was not factored in for the remainder of the questions to allow for a comparative element. Such information is of significance due to the potential for correlation between the extent of and the impact of the care role being performed and where it occurred.

Most respondents reported they commonly cared for a grandmother (24.0%), mother (20.0%) or brother (15.0%), with some (28.6%) providing care to more than one person. Of the ten percent who provided 30 hours or more care a week, the vast majority (9.0%) were female. Over one third (39.0%) provided care seven days a week and one fifth (20.0%) provided care one day a week.

Figure 2 illustrates little difference in duration of the caring role, with just over one fifth (21.0%) reporting between 3-5 years or over 5 years and just under a

¹⁰ <http://www.ark.ac.uk/ylt/2010/YLTquest2010.pdf>

¹¹ http://www.ark.ac.uk/ylt/2010/YOUNG_CARERS/

quarter (24.0%) reporting less than 3 years, The one third (34.0%) of responses indicating care provided for another amount of time comprises less than 12 months or the *Don't Know* option.

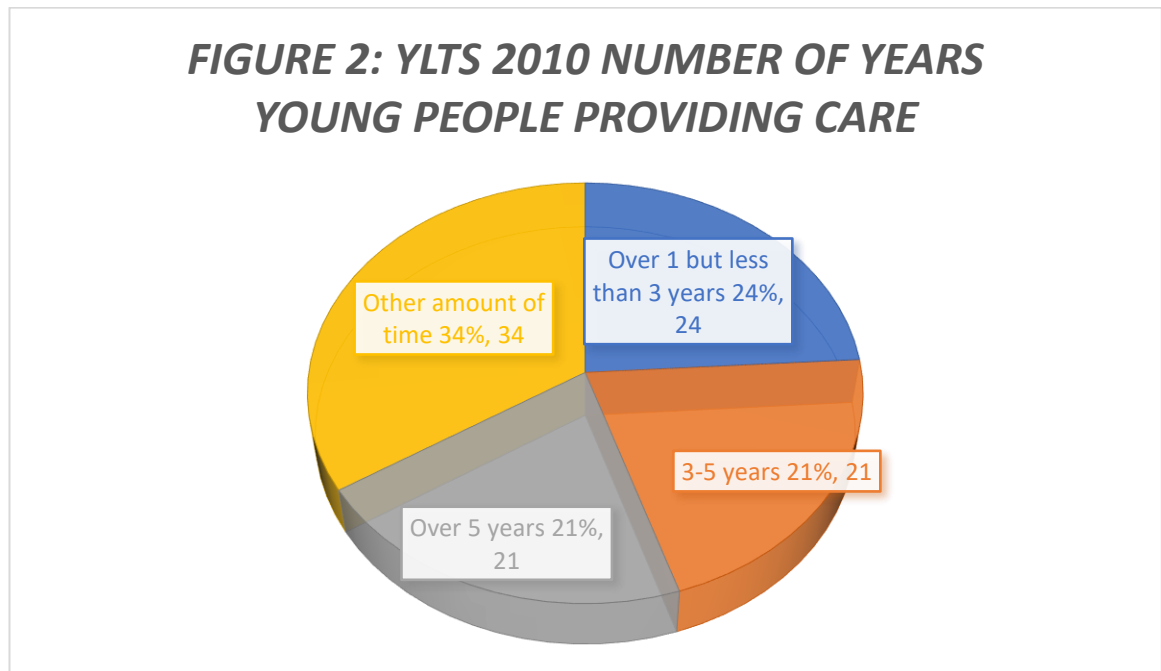


Figure 2: Number of years respondents had been providing care (YLTS, 2010)

Young people's response to how they felt about caring revealed the majority (71.0%) agreed or strongly agreed that they *enjoyed their role*. However, just over a third (39.0%) agreed or strongly agreed that they *worried all the time about the person they cared for when not with them*, with a higher proportion of females (46.0%) agreeing or strongly agreeing with this statement. Overall, a third (33.0%) reported often getting *stressed out due to my caring role*, with a higher proportion of males (43.0%) than females (30.0%) reporting this. Caring for someone was described by just under a quarter (23.0%) of young respondents as something they felt was *private and should not be spoken about outside the family*, with a higher proportion of males (27.0%) than females (21.0%) reporting this.

Figure 3 shows not just the most frequently reported caring tasks in YLTS 2010, notably, it highlights the diverse spectrum of these, ranging from watching over someone, cooking and cleaning to providing more personal tasks such as dressing, toileting and washing.

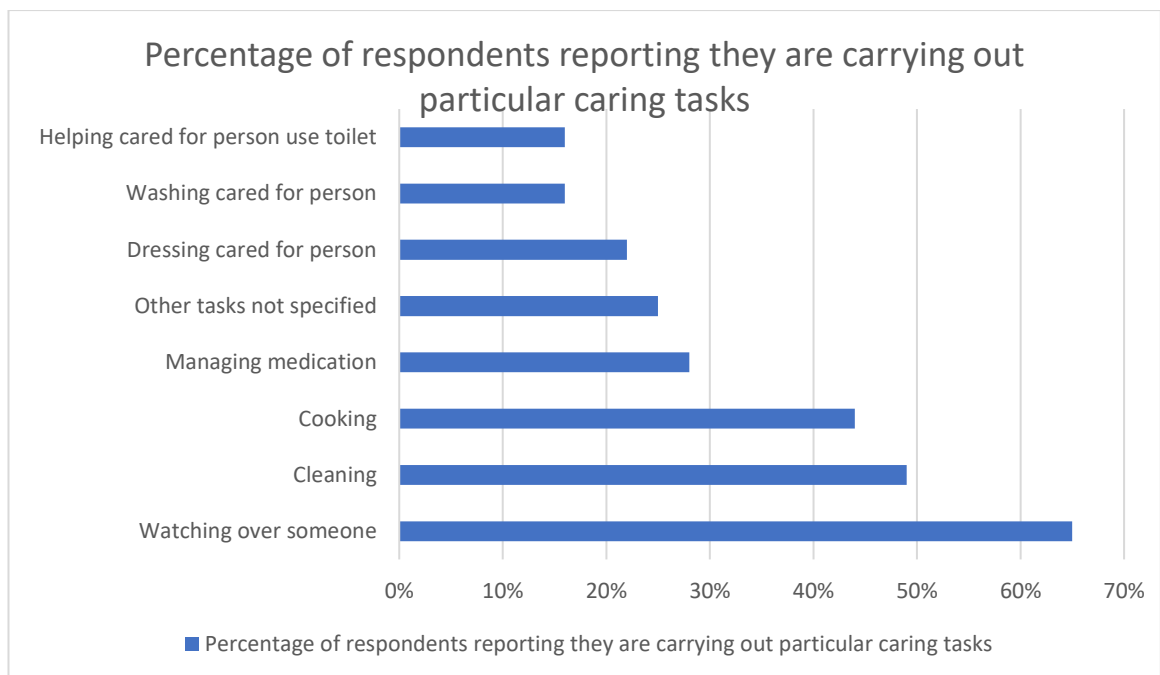


Figure 3: YLTS 2010 Most frequently reported caring tasks

Those young carers providing care received support from a range of sources, including other relatives, G.Ps (27.0%), district nurses (16.0%), home helps (13.0%), social workers (13.0%), teachers (10.0%), counsellors (4.0%), and voluntary organisations (3.0%). Half of participants (50.0%) strongly agreed or agreed that they knew they could *get help from Social Services*, with a smaller proportion (12.0%) disagreeing. With regard to being *fully involved in decisions made about the care of the person* they provide care for, a third of respondents (33.0%) strongly agreed or agreed with this and just over a third (36.0%) disagreed or strongly disagreed.

Socially, just over two thirds (67.0%) of young carers strongly agreed or agreed that *Caring does not stop me going out and doing things with my friends*. Just over a third (39.0%) strongly disagreed or disagreed that they felt guilty about *going out, socialising and leaving the person* that they care for compared to just over a fifth (21.0%) who did feel this way. On the issue of bullying, a majority (85.0%) disagreed or strongly disagreed that they had been *excluded or bullied because they care for someone*, with the remainder *agreeing*, *disagreeing* or opting for *don't know* as their response.

In relation to education, the majority (80.0%) of respondents agreed or strongly agreed that they never missed school because of their caring role, with only a smaller proportion (9.0%) disagreeing or strongly disagreeing. Over two thirds,

(70.0%) strongly agreed or agreed that their schoolwork was not affected by their caring role, however, almost a quarter (23.0%) disagreed or strongly disagreed that this was their experience. More male young carers (81.0%) reported their schoolwork was not affected compared to a smaller proportion (64.0%) of females. Only a minority of young carers (10.0%) reported that teachers gave them support. Regarding out-of-school activities, just over three-quarters of participants (78.0%) strongly disagreed or disagreed that they were *unable to attend out-of-school activities due to my caring responsibilities* with a minority (7.0%) of young carers strongly agreeing or agreeing.

Based on the results of YLTS 2010, the PCC completed *A report of the experiences and circumstances of 16 year old carers* in Northern Ireland. Several significant findings and conclusions were identified, including:

A broad definition of the term “*care*” was identified, with caring being interpreted in a range of different ways.

- The majority of caregiving took place in families where young carers lived with both parents.
- Care provided in a one parent family was most often for the mother.
- Young carers were less inclined to talk about their caring role if it related to a parent.
- Young carers rarely had the one caring task.
- Financially, the presence of a care recipient in a household was associated with an average or below average household income.
- The report noted that few young carers received help or support from an official source such as social workers, teachers or district nurses, relying instead on their own families. This observation raised questions “over the role of social services and the level of support they are able to offer young carer’s”.

Concern about the low numbers of young carers' accessing social services was highlighted, particularly when they knew this could potentially help them.

In relation to young carers and their education, the PCC established there was a clear sign that most did not experience any problems with their schooling - many were still in education, with over 80% disclosing that they planned planning to go on to Further or Higher Education. This suggested that young people remained positive about their futures and saw these goals as achievable.

- Most young carers did not report attendance difficulties, although in a few instances there had been problems with homework completion. The authors compared results from the statements *I am unable to attend out-of-school activities due to my caring role* and *caring doesn't affect my schoolwork* with the actual time in hours and days spent providing care. The results of this comparison suggested that some young carers were experiencing difficulties at school (Ibid, p.24).
- The report identified a negative correlation between the amount of time a young person spent caring and impact on school activity, the more time being given to caring the less time being spent on schoolwork, which could, in time, negatively impact on academic performance. They acknowledged that figures highlighted a group of young people potentially at risk from missing out educationally and needing extra support. The numbers of young people in this situation were regarded however as "too low to draw any definite conclusions" (Ibid, p.7).
- The PCC emphasised that the small number of young carers who seemed to be negatively affected by their caring should not be forgotten or overlooked, especially when formulating services. It recommended that although most did not report major difficulties with their education, including those instances where young people were providing care over thirty hours per week, further investigation was required.

This report concluded that YLT 2010 gave a "limited picture" of the experiences and circumstances of young carers in Northern Ireland and indicated that a more

detailed survey would be both “justified and necessary to arrive at a more informed perspective on this issue” with the issues highlighted above in the PCC report indicating potential areas for further study. Due to the small number of respondents identifying as young carers, it was not possible to perform statistical tests (PCC, 2011). However, by examining a number of variables, correlated information identifying trends relating to the lives of young carers was possible. The authors suggested that young people from a higher socio-economic background were more likely to respond to the survey and that this could perhaps explain why most did not consider themselves as restricted by their caring role when it came to their futures.

2.3.3 The Young Life and Times Survey 2011-2018

YLTS 2011-2013 contained no questions on young carers¹². The 2014 and 2016 YLTS did not include any questions on young carers, however, they did examine how education and youth work encouraged *understanding of particular groups in society and promote the equal treatment of different groups*¹³. One group was *people with caring responsibilities and those without caring responsibilities*. In both surveys, approximately one third of respondents believed their school or youth project/youth club had *encourage[d] understanding* on this subject. However, there was a notable contrast in the responses on whether this had resulted in fellow class members, those attending a youth project/youth club with them feeling *more positive* towards those with a caring role. On average in 2014, almost three quarters (74.0%) of respondents said that it had, whereas in 2016, only a third (33.0%) concurred, a variance of 41.0%. A variation of this question was asked in 2017 and 2018, asking if as a result of being involved in Community Relations Equality and Diversity Education *do you feel more favourable, more unfavourable or just the same regarding equal treatment*, included in the list of groups young people were asked to respond to was *People with caring responsibilities and those without caring responsibilities*. There was little

¹² <http://www.ark.ac.uk/ylt/YLTQuest2011.pdf>;
<http://www.ark.ac.uk/ylt/YLTQuest2012.pdf>;<http://www.ark.ac.uk/ylt/YLTQuest2013.pdf>.

¹³ <http://www.ark.ac.uk/ylt/2014/>

difference in results for each year, on average 26.0% said they felt more favourable than they did before, 73.0% reported no change in how they felt and just 2.0% reported they still felt unfavourable towards this group.

In 2015, one thousand, one hundred and fifty-eight young people completed YLTS, which contained a specific section on young carers¹⁴. These questions were funded via the ARK Ageing Programme through monies received from Atlantic Philanthropies. Compared to YLTS 2010, there were several differences in how a caring role was defined and what the role involved meaning it is not possible to apply a direct comparison between these two years. For example, YLTS 2015 was not as definitive in its definition of young carers as YLTS 2010. YLTS 2010 gave the definition of a young carer as:

“...a child or young person under 18 years of age whose life is significantly affected by caring for a family member who has an illness or disability or has a problematic use of drugs or alcohol. CARING means carrying out everyday tasks such as helping with washing or dressing, cooking and cleaning as well as watching over someone so that they don't hurt themselves. Caring can be one or a combination of these tasks”¹⁵.

In YLTS 2015, the following introduction was given to questions about caring:

Most young people help out at home with, for example, shopping or cleaning. However; some also provide ongoing care and support to someone who is elderly, has a long term illness or disability. Sometimes called 'Young Carers', they help with everyday tasks, such as, helping someone to get washed and dressed, providing someone with emotional support and reassurance, or watching over them so that they stay safe¹⁶.

YLTS 2015 offered a broader definition of the caring role, for example, acknowledging the cared for person may not necessarily be a family member; it also included those who are elderly and those with a long term illness or disability. The survey also gave young people the option of identifying living arrangements: *some live with me and some don't live with me*¹⁷. To ascertain who a young person cared for, some options were newly grouped: for example, family

¹⁴ <http://www.ark.ac.uk/ylt/2015/>

¹⁵ <http://www.ark.ac.uk/ylt/2010/YLTquest2010.pdf>.

¹⁶ <http://www.ark.ac.uk/ylt/2015/YLTquest2015.pdf>.

¹⁷ <http://www.ark.ac.uk/ylt/2015/YLTquest2015.pdf>.

members were linked (such as 'brother or sister', 'grandmother or grandfather'), rather than listed individually. This made direct comparison with previous surveys less defined. Regarding the amount of time spent *looking after people*, the survey included more response options, namely; *30-34 hours per week*, *35 hours or more per week*, *it is hard to put into hours it is just part of my everyday life* and *it is unpredictable as the person I care for has good and bad days*. YLTS 2015 contained an additional question to establish why the young person was providing *special help or extra care*. Response options to *what kind of caring tasks do you have to do* changed in YLTS 2015 to reflect the wider nature of caring rather than a list of practical tasks: these included *personal care*, *physical care* and *emotional care*. Finally, YLTS 2015 asked whether respondents had a person or an organisation they *can go to for help* if they are feeling stressed about their caring responsibilities. The survey concluded with an additional question giving an opportunity to comment if there was *anything else you would like to say about being a young carer*.

Key findings to emerge from YLTS 2015:

- The number of respondents dramatically increased to 1,158 compared to 786 in YLTS 2010, with a higher proportion of males (n=486; 42.0%) represented.
- The proportion of respondents identifying themselves as young carers remained at 9.0%, the same as YLTS 2010, however due to the increased response rate, the number of young carers increased from 71 in 2010 to 104 in 2015.
- Over a quarter (29.0%) of young people had been providing care for over five years, an increase of 8.0% since YLTS 2010.
- The most common care recipient was a grandparent which reflected 2010 survey data (when grandmother drew highest response). However, perhaps due to the new response options, the order of precedence changed to grandparent, sibling, mother and father in 2015 compared to the order of results from 2010 which was Grandmother, mother, brother, father, grandfather and sister.
- Quantifying their caring role, over a third (37.0%) identified *it is hard to put unto hours it is just part of my everyday life* whilst a smaller proportion

(8.0%) indicated *it is unpredictable as the person I care for has good and bad days*.

- The proportion of young people agreeing or strongly agreeing that they enjoyed their caring role increased slightly from 71.0% to 75.0%; there was a slight reduction of 4.0% amongst those agreeing that they felt worried all of the time, and a similarly small reduction of 8.0% in those reporting they felt stressed due their caring role.
- There was a slight increase (2.0%) amongst those disagreeing that they felt *fully involved* in decisions for the person/persons they were providing care to.
- There was an increase (7.0) in the numbers of young people reporting that caring did not stop them going out and a slight decrease (1.0% in each instance) in those saying they were unable to attend after-school activities or having been bullied.
- There was a decrease (7.0%) in the numbers reporting their schoolwork was affected by their caring role and a decrease (4.0%) in those stating their schoolwork had not been impacted by their caring role. However, there was an increase of 3% in those indicating that they had missed school because of their caring role.

2.3.4 Summary

To summarise Northern Ireland Census figures to date have shown an increase in the numbers of young people aged 16 to 24 identified as having a caring role. The Northern Ireland Young Life and Times Surveys have provided further information about the types of caring tasks being undertaken and the nature, duration and impact of this role. The increasing inclusion of questions on young carers in this survey indicates a growing awareness of and interest in young carers living in Northern Ireland, their circumstances and the impact such a role is having on them, including on their education. The Northern Ireland Young Life and Times Surveys is a helpful example of a survey used to establish general information about the situations and experiences of young carers in Northern Ireland, however it is limited in detail on the impact of caring on education.

2.4 Young Carers: NI Specific Policy and Legislation

This section examines Northern Ireland specific policy and legislation relating to young people who provide informal, unpaid care. It will be outlined and discussed under the following headings:

- Carers' policy, strategy and legislation
- Education policy, strategy and legislation
- Children and young people-specific wider policy, strategy and legislation
- Health and well-being
- Child poverty strategy
- Other Northern Ireland reports relating to children and young people.

2.4.1 Carers' Policy, Strategy and Legislation

Since 1989, there has been a range of policy, strategies and legislation relevant to Carers in Northern Ireland. More specifically, young carers have been acknowledged as a distinct group since 2002, with needs and support distinct from adult carers. It is inevitable, therefore, that policy, strategy and legislation is more explicit on the needs of young carers than others.

The *Disabled Persons (Northern Ireland) Act (1989)* was the first visible legislation placing a duty on Health and Social Services Boards (HSSBs) to take into consideration the capacity of those people providing substantial unpaid care, to a disabled person living at home on a regular basis. Since then, the needs of carers in Northern Ireland have been an incremental feature of policy and legislation, featuring in *People First: Community Care in Northern Ireland (1990)*, *People First Care Management: Guidance on Assessment and the Provision of Community Care (1991)* and the *Carers (Recognition and Services) Act (1995)*. None of these, however, explicitly referred to children and young people who provided an informal, unpaid caring role.

Similarly, *Section 75 of the Northern Ireland Act (1998)*, did not directly mention children/young adults as carers, but the Act was the first time the issue of carers was “brought to the attention of decision makers within public bodies”¹⁸. Section 75 placed a duty on public authorities “to promote equality of opportunity” between different groups of people on various grounds, one of which being “between persons with dependents and persons without”¹⁹. The term ‘dependent’ included a person with a long-term sickness or disability who is cared for by someone else (Burns et al., 2015, p.277). The Act was considered “of vital importance to carers as, unlike other Section 75 groups, carers have no other legal protection against discrimination due to their status”²⁰. In relation to young carers and their education, the Act sought to prevent discrimination and promote measures “that facilitate equality of access, attainment, progression and destinations in education for all” (Burns et al., 2015, p.35). The subsequent *Carers and Direct Payments Act (Northern Ireland) (2002)* was the first time in policy and legislation, young people in a caring role were explicitly described as a “child carer” (DHSSPS, 2002, p.30). Article 17A of this Act, focused explicitly on child carers, giving them the right to an assessment or the right to request one to ascertain if they were a child in need and entitled to necessary services²¹. It also enabled young people with caring roles aged sixteen years and upwards to receive Direct Payments “for the services that meet their own assessed needs” (DHPSS, 2002, p.5). The premise of this Act was to “recognise child carers and address their needs by identifying them as a specific group in the *Children (Northern Ireland) Order 1995* and “to treat all child carers as children first and carers second” (Ibid, p.30).

Around the same time, *Valuing Carers: Proposals for a Strategy for Carers in NI, (2002)* specifically identified young carers as a distinct population in need of direct support.²² This proposed Strategy recognised their specific needs differed from adult carers, “because of the potential for adverse impact in the longer term on their educational, social and emotional development” (Ibid, p.28). As a safeguard,

¹⁸ Carers NI (2008) Carers Northern Ireland's response to Section
<https://www.carersuk.org/northernireland/policy/policy-library/section-75>.

¹⁹ <http://www.legislation.gov.uk/ukpga/1998/47/section/75> consulted 17/11/2017.

²⁰ Carers NI (2008) Carers Northern Ireland's response to Section
<https://www.carersuk.org/northernireland/policy/policy-library/section-75>.

²¹ http://webarchive.nationalarchives.gov.uk/20080806202259/http://www.opsi.gov.uk/legislation/northernireland/acts/acts2002/nia_20020006_en_1 consulted 20/10/2017.

²² <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/valuing-carers-2.pdf> p.11.

the Strategy stressed they must be treated as young people or children first and that “a significant level of service” must be provided to the person needing care to prevent “children having to take on inappropriate levels of responsibility” (Ibid, p.28). Recommendations were made for better joined up service delivery between the Department of Health, Social Services and Public Safety (DHSSPS) (including Health Boards and Trusts) and the Department of Education (DE). In 2006, the DHSSPS published ‘*Caring for Carers: Recognising, Valuing and Supporting the Caring Role*’. This strategy was a collaboration between the DHSSPS and the DE and set out a series of recommendations that included: the importance of identifying young carers; access to appropriately tailored information; and awareness-raising amongst teachers in relation to their pastoral role under the Education and Libraries (NI) Order 2003.

Between 2006 and 2009, the DHSSPS issued several Circulars relating to the identification of carers, their role in decisions affecting them and the importance of ongoing support. *Circular HSS (ECCU) 4/2006* was issued to Chief Executives of Health and Social Services (HSS) Boards and HSC Trusts, Chief Officers of HSS Councils and all General Practitioners in November 2006. One key action was that “HSC professionals should be particularly proactive in identifying the presence of older or younger carers” (DSD and DHSSPS, 2006, p.5). *Circular HSS (ECCU) 3/2008* subsequently advocated that “Carers must be true partners” in decision-making, both in relation to the person they cared for and in their caring role²³. Special reference to “younger carers”, was intended to ensure that they did not take on inappropriate care roles and responsibilities. *Circular HSS (ECCU) 2/2009*, reiterated that supporting carers remained “a central objective of community care policy” and reminded Trusts of the statutory duties placed on them by the Carers and Direct Payments Act (Northern Ireland) (2009)²⁴.

At the same time, the *Review of the Support Provisions for Carers (2009)* identified they “are likely to experience high levels of psychological distress, including anxiety, depression and loss of confidence and self-esteem than non-

²³ <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/hss-ccu3-2008.pdf> on 24/07/2019, p.4.

²⁴ <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/eccu2-09.pdf> on 24/07/2019.

carers” (DSD and DHSSPS, 2009, p.22). The review outlined a vision for young carers that protected them from inappropriate caring roles, and supported them to “learn, develop and thrive” and “enjoy positive childhoods” (Ibid, p.23). Several commitments were made, including funding for awareness-raising in schools; producing training materials for GPs and hospital discharge teams; learning from existing support services and using this knowledge to shape planning provision and shaping preventative measures (Ibid). Long term, embedded protections for young carers was prioritised and it was agreed that the Understanding the Needs of Children in Northern Ireland (UNOCINI) assessment framework would be used by all professionals working with children to enable identification of their needs at an early stage (Ibid).

The Health and Social Care Reform Act (NI) (2009), placed a statutory duty on Health and Social Care Trusts “to involve and consult patients, families, carers and local communities in the planning, commissioning, delivery and evaluation of services”²⁵. In August 2010, the DHSSPS launched the booklet ‘*Carers and Discharge: A Carer’s guide to hospital discharge*’. In this context, choice is emphasised, realism around the caring role is encouraged, with all the relevant information provided to inform any decision-making process. The booklet stated that “distinction should be made between a person caring about someone and a person providing care for someone” (DHSSPS, 2010). Discharging staff are urged to consider those who “face additional barriers to services”, with young people under eighteen years old specifically identified. Emphasis is placed on ensuring that young people “do not assume caring roles that will disrupt their education or adversely impact on their development, health or wellbeing” (DHSSPS, 2010) and it is recommended that when a young carer is identified, Children’s Services be consulted.

In 2011, the *Transforming Your Care Review Report* made no reference to young carers. However, the proposed accompanying implementation programme acknowledged young carers and identified support options²⁶. At the beginning of 2017, the Department of Health commenced a reform of adult care and support. In December 2017 the report *Power to People: Reform of adult care and support*

²⁵ <https://www.health-ni.gov.uk/topics/safety-and-quality-standards/personal-and-public-involvement-ppi> on 24/07/2019.

²⁶ <http://www.transformingyourcare.hscni.net/consulted> on 27/08/2019.

in Northern Ireland was published, however, following the protracted collapse of the governing Assembly a final strategy for action has still to be finalised²⁷.

In summary, the policy environment demonstrates that since 1989 there has been increasing recognition of the existence of young carers. More specifically, since 2002, there has been more explicit reference to young carers, emphasis on identifying these young people and prioritising their support needs.

2.4.2 The Education Environment

Education policy, strategy and legislation in Northern Ireland, contain few direct references to young carers. Instead, it is indirectly, through legislation and policy designed to safeguard all children in education that young carers can be supported to reach their full learning potential. These include the *Education and Libraries (NI) Order (2003)* and the *Addressing Bullying in Schools Act (Northern Ireland) (2016)* as well as policies including the *Extended Schools Programme (2006)*, *Every School a Good School (2008/2009)*, the *Pathway to Success Strategy (2012)*, *Miss School Miss Out (2016)*, and the *iMatter Programme (2018)*.

The Education and Libraries (NI) Order (2003) stipulates that schools have a duty of care to pastorally support all pupils, including young carers, as well as other marginalised or disadvantaged groups. In addition, Boards of Governors were given a new legal obligation to take “an active interest in all aspects of a school’s activities that promote pupil welfare”²⁸. Pupil welfare, in this instance, is defined as “all aspects of pastoral care, child protection, pupil behaviour, health and well-being safety and security”²⁹. A similar obligation was placed on Governors through the *Addressing Bullying in Schools Act (Northern Ireland) (2016)* which

²⁷ <https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-full-report.PDF> consulted on 10/04/2020.

²⁸ Department of Education. Circular 2003/13-Welfare and protection of pupils education and libraries (NI) Order 2003. <https://www.education-ni.gov.uk/sites/default/files/publications/de/circular-2003-13-welfare-and-protection-of-pupils.pdf> on 29/07/2019.

²⁹ Department of Education. Circular 2003/13-Welfare and protection of pupils education and libraries (NI) Order 2003. <https://www.education-ni.gov.uk/sites/default/files/publications/de/circular-2003-13-welfare-and-protection-of-pupils.pdf> on 29/07/2019. No page numbers.

sought to protect children and young people by preserving schools as a safe environment and “secure measures to prevent bullying”³⁰.

The *Extended Schools Programme (DE, 2006)* was developed to provide additional support for disadvantaged children and young people to help them reach their educational potential. This Programme was updated in 2012 and the DE identified ten groups who could experience barriers to education. Young carers were not named as one of these groups; this does not mean that they are excluded but, equally, they did not have the profile of being named³¹.

In 2009, *Every School a Good School (DE)* recognised the centrality of teachers in children’s lives and the role of schools in producing well-rounded young people with at least basic literacy and numeracy skills³². Several key principles outlined in the policy are of significance to young people with a caring role. Central to improving academic achievement and addressing underachievement, is focusing on the interests of pupils rather than institutions. through promotion of parity of access and provision for diversity of need. Subsequently, the *Miss School: Miss Out* strategy (2016) encouraged schools to develop their own attendance policy according to the individual needs of their school³³. The strategy advised schools to regard pupil attendance as “influenced by many facets of the school experience”, such as teaching quality, subjects available and the quality of pastoral care offered to pupils³⁴. It also recognised that poor attendance can be due to a range of personal and environmental factors rather than just school-based causes. Although the strategy identified certain groups who were more

³⁰ https://www.legislation.gov.uk/nia/2016/25/pdfs/nia_20160025_en.pdf on 18/07/2019, p.1, p.2.

³² *Every School a Good School- a policy for school improvement. 2008/2009 Department of Education* (<https://www.education-ni.gov.uk/sites/default/files/publications/de/ESAGS%20Policy%20for%20School%20Improvement%20-%20Final%20Version%2005-5-2009.pdf> on 01/08/2019, p.10.

³² *Every School a Good School- a policy for school improvement. 2008/2009 Department of Education* (<https://www.education-ni.gov.uk/sites/default/files/publications/de/ESAGS%20Policy%20for%20School%20Improvement%20-%20Final%20Version%2005-5-2009.pdf> on 01/08/2019, p.10.

³³ December 2016. Department of Education. *Miss School: Miss Out: Improving Pupil Attendance Strategy* <https://www.education-ni.gov.uk/sites/default/files/publications/education/Miss%20School%20%3D%20Miss%20Out%20A%20Strategy%20for%20Improving%20Pupil%20Attendance%20%282%29.pdf> on 30/07/2019, p.15.

³⁴ December 2016. Department of Education. *Miss School: Miss Out: Improving Pupil Attendance Strategy* <https://www.education-ni.gov.uk/sites/default/files/publications/education/Miss%20School%20%3D%20Miss%20Out%20A%20Strategy%20for%20Improving%20Pupil%20Attendance%20%282%29.pdf> on 30/07/2019, p.16.

likely to experience problems with attendance, young carers are not explicitly named. However, theoretically, this means that should schools identify young carers with attendance problems, the strategy encourages schools to formulate their own policies and practices that would be sensitive to their needs. Other Department of Education guidance reinforces the importance of regular school attendance and reminds parents/guardians of their legal duty to make sure children of compulsory school age attend full-time.³⁵ Emphasis is placed on the importance of partnership between parents/guardians and schools. A link Education and Welfare Officer (EWO) is assigned for every school and EWOs can advise and help pupils and parents on practical issues causing absenteeism, signposting or referring to other support agencies, and accompanying parents to school meetings on their child's attendance.

The *iMatter Programme* (2018) replaced the 'Pupils' Emotional Health and Wellbeing Programme' (2005). This programme has relevance for young carers as it is intended to promote "resilient emotional health for all pupils" and provides various resources specifically designed to address issues of concern for young people, including stress, self-esteem and substance abuse³⁶.

The DE and the Department for Economy (DfE), "work closely together" on issues relating to "the education and training provision for 14 to 19 year olds"³⁷. They have a shared interest on quality teaching and learning; careers provision; preventing young people not being in employment, education or training (NEET); STEM and ensuring young people access to courses that are right for them³⁸.

In 2012, the *Pathway to Success Strategy* was launched by the NI Executive and the former Department of Employment and Learning (DEL). This aim of this strategy was that by 2020, every young person would have the opportunity to access education, training, or other tuition for employment³⁹. The strategy recognised this as one of the biggest and most crucial social and economic issues of our time" (Ibid, p.10), particularly for young people who are NEET who,

³⁵ The Department of Education. School Attendance. <https://www.education-ni.gov.uk/articles/school-attendance-0> on 29/07/2019.

³⁶ Department of Education iMatter Programme. <https://www.education-ni.gov.uk/articles/imatter-programme> on 30/07/2019.

³⁷ 14 to 19 Policy. <https://www.education-ni.gov.uk/articles/14-19-policy> on 30/07/2019.

³⁸ 14 to 19 Policy. <https://www.education-ni.gov.uk/articles/14-19-policy> on 30/07/2019.

³⁹ <https://www.economy-ni.gov.uk/sites/default/files/publications/del/del-pathways-to-success-v6.pdf> on 10/07/2019, p.9.

significantly, had poor levels of educational attainment. Young carers were identified in this group and the strategy highlighted the difficulties they experienced whether remaining in education, accessing training or seeking employment. It also signposted a new Youth Service policy to “clearly align the policy and support for youth work in education with wider education priorities” that would meet the needs of groups of young people who may be isolated, marginalised, and at greater risk of social exclusion and poor educational outcomes (Ibid, p.36). This policy, entitled ‘Priorities for Youth - Improving Young People’s Lives through Youth Work’ was launched in 2013 and recognised the importance of improving the social and personal skills of young people and keeping them “actively engaged in a learning process” (DE, 2013, p.ii). The newly formed Education Skills Authority (ESA) was given the statutory duty to ensure, deliver and support youth work “in line with DE’s priorities” (Ibid, p.28) as the means of closing performance gaps between young people and increasing their equality and access. It further states that targeted provision will be directed to certain groups, including young carers, those who are, or at risk of becoming, NEET.

In summary, this section highlights how, through direct and indirect policy and legislation, young carers should be supported in their education to reach their full potential. As a group, young carers are not explicitly mentioned in many statutory documents, even when examples of disadvantaged or marginalised groups are prioritised. In the next section, broader policies, strategies and legislation relevant to the lives of children and young people are discussed as these also have an impact on young carers.

2.4.3 Children and young people: wider policies, strategies and legislation

The introduction of the *Children (Northern Ireland) Order (1995)* underpinned all subsequent policy in Northern Ireland relevant to young carers. The Order placed a duty on all authorities “...to safeguard and promote the welfare of children”, and if a child is defined as being “in need” to provide “a range and level of social services appropriate to those children’s needs” (Section 18 (1)(a)). A young person with a caring role can be defined as a child (in need) due to the impact it can have on their health, social and educational development (The Children

(Northern Ireland) Act, 1995). Prior to this Act, *The United Nations Convention on the Rights of the Child (UNCRC)* had been ratified by the United Kingdom in 1992. Young carers occupy a distinctive position in relation to the Convention. In theory, they should have the same access to rights as other children as they are, first and foremost, a child; however, their specific needs have not always been upheld. For example, Article 3 advocates acting in the best interests of the child, Article 12 promotes the voice of the child to be heard in matters affecting them, Article 28 states that “[E]very child has the right to an education” and Article 29 outlines that “[E]ducation must develop every child’s personality, talents and abilities to the full”⁴⁰. The most recent report on the UNCRC in Northern Ireland (2014) acknowledged the prevalence of young carers in NI⁴¹. Additionally, the Commissioner for Children and Young People, in her statement on the state of children’s rights in NI, highlighted bullying of young carers as an enduring issue and endorsed a responsive anti-bullying policy.

The UK Government’s *‘Every Child Matters: Change for Children’ Strategy (2004)*, preceded the implementation of *‘Our Children and Young People- Our Pledge: A Ten Year Strategy for Children and Young People in Northern Ireland 2006-2016’* (OFMDFM, 2006). This Strategy included a rights-based approach towards fulfilling its pledges, promoted prevention and early intervention and improving the quality of life chances for all children and young people. This would be achieved through provision of quality universal services, working in co-ordinated partnership across all sectors.

The *Northern Ireland Children and Young People’s Plan (2011-2014)* established The Children and Young People’s Strategic Partnership (CYPSP) and was led by Chief Executives from statutory, voluntary and other organisations/agencies with the specific aim of improving the lives of all children and young people. A key outcome was a *Young Carers Action Plan (2011-2014)*, which was implemented by a Regional Sub Group on Young Carers⁴². The Sub Group promoted young carers first and foremost as children and young people and included a longer

⁴⁰ Summary of UNCRC where quotes are from, https://www.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_summary-1.pdf.

⁴¹ Children’s Law Centre and Save the Children NI (2015) Northern Ireland NGO Alternative Report. Submission to the United Nations Committee on the Rights of the Child for Consideration during the Committee’s examination of the United Kingdom of Great Britain and Northern Ireland Government Report (May 2014).

⁴² https://www.cypsp.org/wp-content/uploads/2014/02/young_carers_action_plan_2011-2014.pdf on 15/07/2019, p.1.

term plan to develop vital early intervention, so that they received the “additional support they may require” (Ibid, p.3).

The updated *Northern Ireland Children and Young People’s Plan (2014-2017)* continued to target the development and maintenance of jointly commissioned and integrated planning across sectors and agencies as a means to improve the realisation of children’s rights and wellbeing⁴³. The Plan prioritised again the needs of vulnerable groups within “an early intervention info-structure” so that support was provided before family circumstances deteriorated to children in need. Young carers were again specified as a vulnerable group and retained the oversight of a Regional Sub Group.

Perhaps one of the most important pieces of legislation came into effect in 2015. The *Children’s Services Co-operation Act (Northern Ireland)* was significant in its commitment that government should work towards joined up policy for children and young people. The Act was intended to:

“... require co-operation among certain public authorities and other persons in order to contribute to the well-being of children and young persons; to require the adoption of a children and young person’s strategy; and for connected purposes”⁴⁴.

This Act encapsulated much previous policy but put it on a stronger, more accountable footing and also informed the development of the updated *Children and Young People’s Strategy for Northern Ireland (2017-2019)*⁴⁵. The Children and Young People’s Unit within the DE assumed lead responsibility for its development. Consultation on the draft Strategy closed on 31st March 2017; however, with the collapse of the Northern Ireland Assembly in January of that year, it was not enacted.

In December 2019, dependent on the formation of an Executive to adopt the Executive Strategy, a cross-departmental Children and Young People’s Strategy was published⁴⁶. It again placed particular emphasis on the importance of early

⁴³ https://cypsp.hscni.net/wp-content/uploads/2016/03/cypsp_plan_14_17.pdf on 11/07/2019, p.3.

⁴⁴ https://www.legislation.gov.uk/nia/2015/10/pdfs/nia_20150010_en.pdf on 17/07/2019, p.1.

⁴⁵ <https://www.education-ni.gov.uk/articles/children-and-young-people> on 17/07/2019.

⁴⁶ <https://www.education-ni.gov.uk/publications/children-and-young-peoples-strategy-2019-2029> on 10/04/2020.

intervention and prevention alongside age appropriate actions. This strategy explicitly states it seeks to “ensure children and young people acting as carers receive the support they need to fully undertake their education and have opportunities to relax, socialise and have breaks from their caring responsibilities” (p.79) . Young carers are also listed as an area of greatest focus - to improve support for them.

In summary, since 2011, Children and Young People policy strategy acknowledges and seeks to address the needs of young carers. The following section will examine health and well-being policy, strategy and legislation of relevance to young carers.

2.4.4 Health and Well-being

The Public Health Agency has a duty in Northern Ireland to “meet and promote the universal health and social well-being needs of all children and young people”⁴⁷. The Agency states that “a public health approach is the best way of making life better for children, ensuring they are safeguarded and where necessary protected”⁴⁸.

The vision of the Northern Ireland Regional Family and Parenting Strategy *‘Families Matter: Supporting Families in Northern Ireland’*, launched in 2009 by DHSSPS was that:

“All children and young people are valued during childhood....reach their potential and have the opportunity to lead full, healthy and satisfying lives by becoming active contributors to their community through

⁴⁷ Public Health Agency. (2016) Safeguarding Children and Young People Policy <https://www.publichealth.hscni.net/sites/default/files/directorates/files/Revised%20Safeguarding%20Children%20and%20Young%20People%20Policy%20July%202016%20%20V2.0.pdf>. Consulted on 29/07/2019.

⁴⁸ Public Health Agency. (2016) Safeguarding Children and Young People Policy <https://www.publichealth.hscni.net/sites/default/files/directorates/files/Revised%20Safeguarding%20Children%20and%20Young%20People%20Policy%20July%202016%20%20V2.0.pdf>. Consulted on 29/07/2019.

participating socially, educationally and economically in the life of the community”⁴⁹.

The Strategy prioritised improved outcomes in the health and well-being of children and young people. In line with many other policies, it promoted an integrated approach, early intervention and a coordinated approach from Government and other agencies in the developing policy for children and young people.

More recently, *Making Life Better: A Whole System Strategic Framework for Public Health in Northern Ireland (2013-2023)* contained two themes of particular importance to children and young people and their transition from childhood into adulthood - “Giving Every Child the Best Start” and “Equipped Throughout Life”⁵⁰. Recognising the importance of education in the social, emotional, physical and cognitive development of children and young people, emphasis again was placed on early intervention and a “sustained commitment to children and young people throughout their school years”⁵¹. Specific vulnerable groups are identified as especially at risk; the list is not exhaustive but young carers are not explicitly mentioned.

Following the 2016 report ‘Systems Not Structures Changing Health and Social Care’, the *Health and Wellbeing 2026-Delivering Together Plan* was launched⁵². This plan promoted a future where people are “supported to keep well in the first place”, be in control of their own health and wellbeing and anticipating the support and care needs of individuals⁵³. The contribution of carers is described as “enormous” as they provide the greatest amount of caring responsibilities for their

⁴⁹ DHSSPS. March 2009. Families Matter: Supporting Families in Northern Ireland. Regional Family and Parenting Strategy. https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/families-matter-strategy_0.pdf. p.16.

⁵⁰ https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/making-life-better-strategic-framework-2013-2023_0.pdf on 15/07/2019, p.9.

⁵¹ https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/making-life-better-strategic-framework-2013-2023_0.pdf on 15/07/2019, p.45.

⁵² <https://www.health-ni.gov.uk/publications/health-and-wellbeing-2026-delivering-together> on 19/07/2019.

⁵³ <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf> on 24/07/2019, p. 10.

loved ones⁵⁴. Young carers were identified as needing help and support just to do the things that young people do”⁵⁵. This plan highlighted;

“growing evidence that children who experience adversity in childhood are far more likely to experience health issues in adult life.... more likely to perform poorly in school, more likely to be involved in crime and more likely to experience poverty and disadvantage in adult life”⁵⁶.

2.4.5 Child Poverty Strategy

The Child Poverty Act (2010) sought “to define success in eradicating child poverty and create a framework to monitor progress at a national and local level”⁵⁷. The promises outlined in the Act were articulated in a series of time-bound targets although these have since been repealed by Government and replaced with a statutory duty to publish an annual report on the extent and educational attainment of children in poverty. Removal of this accountability measure was noted by the UN Committee on the Rights of the Child (2016), who noted that the rate of child poverty remains high, with NI experiencing particular disadvantage. In 2016, the NI Executive published the Child Poverty Strategy⁵⁸.

2.4.6 Other Northern Ireland Reports Relating to Young Carers, Children and Young People

Several Northern Ireland based studies identify a link between poverty and poor parental ill health/disability (Child Poverty Alliance, 2014; Monteith et al., 2013; Monteith and McLaughlin, 2004). These indicate a possible correlation between

⁵⁴ <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf> on 24/07/2019, p. 17.

⁵⁵ <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf> on 24/07/2019, p. 17.

⁵⁶ <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf> on 24/07/2019, p. 8-9.

⁵⁷ <https://www.legislation.gov.uk/ukpga/2010/9/notes/division/3> on 15/07/2019.

⁵⁸ NI Executive (2016) Delivering Social Change: The Executive’s Child Poverty Strategy.

<https://www.communities-ni.gov.uk/sites/default/files/publications/ofmdfm/child-poverty-strategy.pdf> on 05/05/2020.

poor parental health and poverty and the increased probability of a young people taking on a caring role in already disadvantaged circumstances. Monteith and McLaughlin (2004) reported that children living in Northern Ireland who were living with a parent with a physical disability or ill health were more likely to be living in severe or non-severe poverty compared to their peers. Statistically, the report found that approximately one quarter of young people living in poverty “had one or more parent with a long-standing illness, health problem or disability” (p.24).

Similarly, Monteith et al., (2013), acknowledged “a strong correlation between deprivation and poor educational achievement” and established that children from poorer families were inclined to have lower educational attainment and lower levels of education post sixteen years old than their peers who were better off (p.31). Young people living with parents who have poor mental health conditions were described as “more likely to struggle in terms of educational attainment and participation in education” with the significance/impact of maternal mental health highlighted in particular (Ibid, p.35). Poverty was described as a particular contributor to poorer outcomes for both mother and child.

In November 2014, The Child Poverty Alliance⁵⁹ published a report entitled ‘Beneath the Surface: Child Poverty in Northern Ireland’. The report established a connection between school achievement and income, with a sizable disparity identified between children from better off families and those children living in poverty. It further highlighted young people living in a household with a disabled parent or sibling and with a caring role were “most likely to experience poverty” (Ibid, p.vi). Not only does this reinforce the relevance of UK wide Child Poverty Strategy to Northern Ireland, it draws attention to how the education of those young people with a caring role may be impacted, including, not having correct school uniform, no extra-curricular activities or school trips, not having necessary books and the equipment a minority of young people conveyed that they did not have internet at home. These impacts caused additional issues for young people such as

⁵⁹ The Child Poverty Alliance was established in 2008 “as a loose alliance of organisations to raise awareness of child poverty and to campaign to end child poverty within Northern Ireland” <http://www.ci-ni.org.uk/child-poverty-alliance> consulted on 31/01/2018.

confrontation with teachers, social exclusion and difficulties producing printed homework or homework's on USB (Ibid, p.100-101).

An Office of First Minister and Deputy First Minister (OFMDFM) commissioned research study (2015) examined young people's use of ICT, their amount of screen time and its impact on their GCSE attainment. The findings of this study, in addition to what was highlighted by Child Poverty Alliance (2014), Monteith et al., (2013) and Monteith and McLaughlin (2004) identified a potential area where young carers need specific support. A link was identified between young people from lower income families and the small number of pupils identified as not having access to a computer at home (a significant percentage of the same young people entitled to Free School Meals). This research reported that young people "who do not have access to a computer or laptop achieve significantly poorer outcomes at GCSE" and compared to their peers are at a considerable disadvantage (Ibid, p.69).

In March 2015, The Equality Commission for Northern Ireland commissioned research on education inequalities in Northern Ireland giving consideration to the levels of educational access, attainment, progression and destination across the nine equality grounds" which included dependant status (Burns et al. 2015, p.7). The term *Dependant* was defined as including "dependent child/children, or a person with a long-term sickness or disability who is cared for by someone else" (Ibid, p.277). Young carers were identified as a group experiencing noteworthy levels of disadvantage and specific barriers to education (Ibid, p.300). More specifically, six themes were identified as barriers to education for carers of sick/disabled relatives: the unpredictable nature of illness and a caring role, financial pressure, the definition of caring, transition to third level education, "identity" and "family friendly services" (Ibid, p.295-296). Stakeholders reported a need to differentiate between the needs of carers and young carers and parents in relation to education.

A significant gap was noted in the support available to young carers once they turn eighteen when they are no longer eligible to the support they received under children's services and are transitioning to adult services if required. Once young carers leave school, they have difficulty accessing support which could help them to enter further or higher education or employment. The Report identified that whilst family friendly services focused primarily on the needs of students who are

parents, the educational inequalities faced by carers will grow due to a predicted increase in the ageing population.

Seven recommended enablers to education were outlined for those with a caring role. Prominence was given to making young people with a caring role a priority in education and the need for universities to target students who may have missed out on education because of caring responsibilities. Disaggregated carer statistics were recommended to differentiate between parenting and caring so the needs of each groups can be highlighted. The provision of respite and day care to support carers should be tailored around their needs, rather than them having to fit with service providers. This would help facilitate carers' participation in education/study. The adoption of flexible learning principles and short courses made educational opportunities more open to carers. The way courses are marketed had potential to make "a big difference in terms of equal access to education" and having "'taster' courses" was noted as helpful for those outside of education to build their confidence and help them find new interests (Ibid, p.298). Any stigma attached to being a carer in education has to be addressed. Remedial action included minimising difficulties in access; often, carers events took place during the day that conflicted with caring responsibilities. Due to corresponding financial pressures, there was a need for carers' allowance to keep pace with inflation and for education institutions to have greater awareness of grants available to carers. Burns et al., (2015) cautioned that in moving forward and addressing educational inequalities there is an absence of robust and/or available data on the educational attainment, progression and access of particular groups including carers which in turn thwarts progress being made on rectifying inequalities.

In 2016, research funded by OFMDFM and carried out by The National Children's Bureau Northern Ireland (NCB) examined the experiences of young people in Northern Ireland "at risk of disengaging from education, training or employment" (OFMDFM, 2016, p.10). Their definition of NEET is a young person "if they are aged 16 to 24 and not in employment, education or training (full time or part-time)" (OFMDFM, 2016, p.6). This report acknowledged that despite a downward trend in levels of young people described as NEET, little is known about the barriers they encounter and there remains a considerable proportion whose life chances will be influenced by experiences at school and transition from secondary to

further education (OFMDFM, 2016). This is of significance as young people who are carers have previously been identified in the 2012, Pathway to Success Strategy as a group at risk of being NEET and having difficulties transitioning/progressing with their education.

In September 2017, The Health and Social Care Board, The Education Authority, Action for Children, Barnardo's NI, Carers Trust NI, The Children and Young People's Strategic Partnership, Young Carers Regional Sub-Group and GingerbreadNI, collectively produced the information document 'Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff' (HSCB, 2017). This was the first document of its kind in NI, mirroring what had already been produced in England and Wales. The collaboration between these groups was motivated by a growing awareness of on the impact on educational attainment of being a young carer and the role of schools in acting as a safeguard in such circumstances.

This document defined young carers and gave details about the impact of a caring role and types of support they may require (Ibid). It emphasised that young carers need support as their "personal and physical development, physical and emotional health, education and social opportunities can all be affected by the family situation and their caring role" (Ibid, p.4). Also included were, examples of good practice, a support framework, recommendations and for schools and information on the support services/options available to young carers in Northern Ireland (Ibid).

2.5 Conclusion

The NI Census figures, and the Northern Ireland YLTS provide useful insights on the potential number of young people with a caring role living in Northern Ireland, with the YLTS data providing valuable insights on their life and education circumstances. Since 1989, there has been gradual recognition of the role of carers in Northern Ireland policy, strategy and legislation. It was, however, 2002 before young people were explicitly acknowledged through the term child carer (DHSSPS, 2002). Education policy, strategy and legislation contains limited

reference to young carer's rather it is through indirect policy reference that they should be supported to achieve their potential. There is an emphasis throughout on early intervention and prevention.

A link has also been identified between poverty, parental ill health and disability with poverty recognised as negatively impacting on a young person's academic achievement (OFMDFM, 2015; Child Poverty Alliance, 2014; Children and Youth Programme, 2013; Montieth and McLaughlin, 2004).

With this Northern Ireland context established, the next chapter will focus on the research literature relating to young carers aged sixteen to twenty-four in education retrieved from a systematic literature search and follow up searches in order to better understand their experiences and the potential challenges regarding education that they face.

3.0 Literature Review

3.1 Introduction

The literature review is divided into two sections and an overall conclusion. Section 3.2 concentrates on the peer-reviewed literature relating to young carers aged sixteen to twenty-four in education retrieved by the systematic literature search (see Appendix One). Section 3.3 focuses on the non-peer reviewed literature (including policy documents) retrieved from both the systematic literature search and subsequent follow up searches for grey material.

The overall conclusion of Section 3.2 and 3.3 identifies gaps in the literature and reinforces the need for research on the educational impact of young carers in Northern Ireland.

Following a systematic literature search (see Appendix One), this following section seeks to:

- Provide a thematic narrative of the peer reviewed literature retrieved relating to young carers aged sixteen to twenty-four and education.
- Analyse the background information of these peer reviewed articles and the numbers and type of sample participants.
- Outline the recommendations being made for practice and areas highlighted for future study.

3.2 The peer-reviewed literature

3.2.1 Introduction

The systematic search strategy retrieved sixty peer reviewed empirical studies based on the inclusion criteria that articles must cover ‘young carer’s aged 16-24’ and ‘education’. This was ascertained through consulting abstracts and full documents where necessary. Upon reading and inputting details of these articles into a Data Extraction Table (see Table 3), ten of these articles were identified as not relevant. Upon closer examination, participants in studies carried out by Assaf (2016); Doutre et al., (2013); Lloyd (2013); Hwang (2010) and Banks et al., (2002) were not within the remit of the 16 to 24-year-old age criteria. The studies of Cassidy et al., (2014); Nichols et al., (2013); Sherwood et al., (2008); Earley et al., (2007) and Shifren and Kachorek (2003) were also classified as not relevant to the study as they did not contain information relating to young carers and education. This left fifty peer-reviewed papers, which will be reviewed in detail in this section.

Table 3: Headings used in Data Extraction Table

First Author, Date and Country	Design and Theory	Sample- Participants	Data Collection	Main findings relating to Young Carers and Education

3.2.2 Background details of articles

The country with the highest number of research studies retrieved was GB with nineteen, over twice as many as the second highest country Africa with eight, followed by Australia with seven, USA with six and Canada with three. Table 4 provides a full breakdown of the countries of research included in the articles retrieved.

Table 4: Country of research breakdown

Country	Number of Studies
GB	19
Australia	7
USA	5
Canada	3
Zimbabwe	3
South Africa	2
Austria	1
China	1
Iceland	1
Ireland	1
Kenya	1
Netherlands	1
Norway	1
Pakistan	1
Tanzania and Zimbabwe (dual location)	1
Unknown	1
USA & Zimbabwe (dual location)	1

It should be noted that of all nineteen studies identified as originating in GB, while nine of which contained no specific details as to the studies location within GB,

only one was Northern Ireland specific and another included both England and Northern Ireland.

Interviews were the most prevalent form of data collection and were used in thirty three of the fifty studies whilst questionnaires were the second most popular method used in eighteen studies (see Table 5). More than half of the studies (n=27) used one method of data collection, with a smaller proportion using multiple methods (Table 6).

Table 5: Breakdown of data collection techniques used in order of frequency

Data Collection Technique	Study Prevalence
Interviews	33
Questionnaires/Surveys	18
Focus Groups	7
Writing/Drawing/Essay Writing	3
Document Reviews	2
Group Discussions	2
Observations	2
Statistical Analysis	2
Group Interviews	1
Photographs and Life Story Book	1
Poster Making	1
Story Boards	1

Table 6: Numbers of data collection methods used

Number of Data Collection Methods Used	Study Prevalence
No method outlined	2
One Method	27
Two Methods	13
Three Methods	8

3.2.2.1 Conceptual and theoretical approaches

A range of theoretical frameworks and conceptual approaches were applied in twelve of the studies. See Table 7 for details.

Table 7: Theoretical approaches used

Details of Conceptual/Theoretical Approach Used in Alphabetical Order	Authors Details and Date of Publication
Bounded Agency Approach	Hamilton and Adamson (2013)
Bronfenbrenner's Ecological Theory	Cluver et al., (2012)

Disability Perspective, Social Psychology Perspectives and Sociology of Childhood Perspective	Banks et al., (2001)
Feminist Concept of Provisioning and Grounded Theory	Lieghio (2015)
Framework of Common Experience	Roche and Tucker (2003)
Realist Biographical Approach	Heyman and Heyman (2013)
Social Capital Theory	Barry et al., (2011)
Social Care Theoretical Framework	Cass et al., (2009)
Social Care Theoretical Framework	Smyth et al., (2011)
Stress and Coping Framework	Pakenham and Bursnell (2006)
The Model of Experience and Construction of Familial Care	Nagl-Cupal et al., (2014)
The Vancouver School of Phenomenology	Bjorgvinsdottir and Halldorsdottir (2014)

As the above table shows, the Social Care Theoretical Framework was the only recurrent approach used (Smyth et al., 2011; Cass et al., 2009). In these instances, this framework was used to examine the circumstances through which young people take on a caring role, to identify gaps in service provision and the implications of policy determining the level and type of care being provided. Within this framework, caring is described as occupying time for a young carer that would otherwise be allocated by something else for example education or social activities. The care being provided may not be recognised as such but seen as part of family responsibilities and obligations. Researchers engaging with this approach, identified young carers as “active participants” within private and public spheres (Smyth et al., 2011, p.510). Here they are engaged in “reciprocal relationships of care” making considerable contributions to the wellbeing of their family and communities - especially those they are providing care to while “incurring personal costs” (Cass et al., 2009, p.44). The Social Care Theoretical Framework is a very linear, prescriptive approach whereas a young person’s experience of education is not something that exists within a vacuum. A young person’s education is ultimately impacted upon by the scenarios and issues they face not just within their place of education but outside their place of education as well for example by their family and social spheres.

Another framework of interest to the researcher was the Bounded Agency Approach used by Hamilton and Adamson (2013). In their research, this approach was used to explain the decisions and rationale behind future ambitions of young carers and how they can be moulded “by the barriers and contexts in which they find themselves” (Hamilton and Adamson, 2013, p.101). This approach focuses on individuals as actors, who have a past and ambitions for the future that shape the present and are combined with actors “subjective perceptions of the structures they have to negotiate, [and] the social landscapes which affect how they act” (Evans, 2007, p.17). The Hamilton and Adamson model is a useful one but, ultimately, it did not allow the more fluid holistic approach offered by Bronfenbrenner. The researcher’s insight as a professional indicated Bronfenbrenner’s fluid interpretation as more relevant to understanding young carer’s educational experiences.

Consequently, Bronfenbrenner's ecological systems theory was adopted for this research due to the porous and fluid nature of the model between levels as this

reflects the complexity of being a young carer with the significant interaction between and the impact from the various levels of environment in a young carers life (See Section 1.4). Admittedly, it is not a model that has been extensively used in education and social science research, but it has been utilised by others researching young carers and it is the researcher's intention that adopting this approach for this research will be of benefit or use to other researchers (Choudhury, 2020; Cluver et al., 2012; Banks et al., 2001).

3.2.2.2 The research samples

3.2.2.2.1 Young carers and others

Twenty-three of the articles included participants in addition to young carers. These studies spanned different age ranges, conditions and circumstances, with participants including parents, care organisation staff, associated professionals and school staff. Five articles provided a comparative perspective between young carers and young non-carers (Nagl-Cupal et al., 2014; Sieh et al., 2013; Warren, 2007; Pakenham et al., 2006; Pakenham and Bursnall, 2006). The sample of Ferraro (2002) consisted of young adult carers and middle-aged adult carers. Aldridge and Becker (2003) engaged a combination of young carers and former young carers. Roche and Tucker (2003) used research carried out with young carers and their parents between 1997-2000 alongside questionnaires with young carers' projects and young people with Myalgic Encephalomyelitis (ME) for comparison. Young carers and staff from young carers' projects and associated professionals were the focus of three research projects (Fives et al., 2013; Heyman and Heyman, 2013; McAndrew et al., 2013). Young carers and their parents were consulted in the research of Bauman et al., (2006) and Roche and Tucker (2003). Three research projects involved young carers, their parents and support professionals (Evans, 2011; Aldridge, 2003; and Banks et al., 2001⁶⁰). Skovdal (2011) and Tatum and Tucker (1998) engaged young carers, the cared

⁶⁰ The inclusion of Banks et al (2001) in this category refers to Study One only.

for person and other family members. Torp et al., (2013) focused on care receivers and unrelated young carers. The research of Robson et al., (2006) had a sample comprising of young carers, primary school children, guardians, local leaders and young people who had been identified as dropping out of school or had poor school attendance in the previous year. Banks et al., (2001) included school pupils, parents/carers and young carers. Pupils from fifty-four schools made up the sample used by Diaz et al., (2007) and random sampling of household members and children formed the sample of Pufall et al., (2014). Szafran et al., (2016), Lackey and Gates (2001) and Lewis and Meredith (1988), focused on former young carers as their research sample.

3.2.2.2.2 Absence of young carers in research sample

Six articles outlined research that did not include any young carers or former young carers; rather they focused on the perspectives of others based on professional or personal observations. The research of Stamatopoulos (2015) involved five directors from three young carer's services, Liegghio (2015) consulted ten lone mothers and Skovdal et al., (2013) researched using ninety members of a community group. Gray et al., (2010) and Gray et al., (2008) consulted with sixty-five professional participants from statutory, voluntary and primary care trusts and Manderson and McCune (2004) reviewed the case notes of females who had children aged 0-17.

3.2.2.2.3 Government data

The research of Hill et al., (2011) and Cass et al., (2007) utilized government statistics. Hill et al., (2011) used quantitative data from the Australian Bureau of Statistics from the 2006 Census of Population and Housing with data collected from one hundred and twenty thousand young people aged fifteen to twenty four years old identifying themselves as providing care. Cass et al., (2007) analysed the Australian Bureau of Statistics (ABS) Survey of Disability, Aging and Caring (SDAC) that identified over three hundred and forty eight thousand young people providing care for at least six months (Cass et al., 2007).

3.2.2.2.4 Numbers of young carers involved in studies

For research involving young carers, Table 8 provides a breakdown of the numbers in the samples.

Table 8: Numbers of young carers in research samples

Number (in categories) of Young Carers in Research Sample	Number of Studies in Category	Authors of Studies within Category	Number of Young Carers in Sample
0-10	6	1.Torp et al., (2013) 2. McAndrew et al., (2012) 3. Bauman et al., (2006) 4. Robson et al., (2006) 5. Ferraro (2002) 6.Coombes (2001)	10 6 9 9 (Minimum) 10 1
11-20	9	1.Bjorgvinsdottir and Halldorsdottir (2014) 2.Heyman and Heyman (2013) 3.Barry (2011) 4.Evans (2011)	11 13 20 11

		5.Warren (2007)	12
		6.Martin (2006)	13
		7.Eley (2004)	11
		8.Gates and Lackey (1998)	11
		9. Aldridge and Becker (1993)	15
21-30	3	1.Fives et al., (2013)	26
		2.Thomas et al., (2003)	21
		3.Tatum and Tucker (1998)	24
31-40	4	1.Javed et al., (2015)	40
		2.Kavanaugh (2014)	40
		3.Hamilton and Adamson (2013)	33
		4.Aldridge (2003)	40
41-50	3	1.Skovdal (2011)	48
		2.Zhang et al., (2009)	47
		3.Pakenham and Bursnall (2006)	48

51-100	4	1.Moore et al., (2009)	51
		2.Roche and Tucker (2003)	60 (Minimum)
		3.Smyth et al., (2011)	68
		4.Pakenham et al., (2006)	100
101-300	3	1.Roche and Tucker (2003)	120 (Maximum)
		2.Sieh et al., (2013)	161
		3.Banks et al., (2001)	164
301-500	4	1.Lane et al., (2015)	349
		2.Nagl-Cupal et al., (2014)	335
		3.Cassidy and Giles (2013)	329
		4.Cluver et al., (2012)	352
501+	1	Diaz et al., (2007)	1391

In the case of Robson et al., (2006), the number of young carers present in the research sample is described as being a minimum number as it is unclear exact overall numbers of young carers involved in the three studies undertaken. The number nine was recorded as nine young people were explicitly mentioned as participants in Study Three as having “caring responsibilities” (Robson et al., 2006, p.23). The assumption was also made, as the article wording was vague, that the work of Roche and Tucker (2003) involved a minimum of sixty young carers as it was stated “over 120 interviews were conducted...involving young people and their parents” (Roche and Tucker, 2003, p.443). The phrase “young people” being used to describe “young people who carry out, or had carried out, major caring roles within the context of the family” (Roche and Tucker, 2003, p.443).

There was no indication of numbers of young carers in the samples of by Pufall et al., (2014), Cooklin (2010) and Underdown (2002) and for this reason they have not been included in Table 8.

The most common number of young carers included in a sample the 11-20 range and this was the case in nine studies, followed by 0-10 range (six cases), 31-40 range (four cases) and 300-400 range (four cases). The study with the highest number of young carers (one thousand, three hundred and ninety one), was obtained by young people identifying themselves as carers out of twelve thousand, six hundred and eighty one students based over fifty four schools (Diaz et al., (2007).

In the four studies including former young carers, the sample spanned four to fifty-one participants (Table 9).

Table 9: Numbers of former young carers involved in research

Research Author	Number of Former Young Carers Involved in Research
Szafran et al., 2016	5
Lackey and Gates 2001	51
Lewis and Meredith 1998	41
Aldridge and Becker 1993 ⁶¹	4

3.2.2.3 Limitations of peer-reviewed studies identified

Based on the examples of Lane et al., (2015), Liegghio (2015), Nagl-Cupal et al., (2014), Bjorgvinsdottir and Halldorsdottir (2014), Cassidy and Giles (2013), Moore et al., (2009) and Torp et al., (2013) who presented a specific 'limitations' section, what follows is a discussion of the limitations of the peer reviewed studies. The limitations of these studies were based on the types of research participants used, sample sizes, the level of detail given about participants and how they were recruited, the method of study and analysis used, whether or not ethical approval was outlined and the lack of quantification and supporting evidence during the reporting of research results.

⁶¹ This research also included current young carers.

The use of former young carers to research the experience has certain limitations. Lackey and Gates (2001) write that such a retrospective study can lead to “some exaggerated lapses in recall” (Lackey and Gates, 2001, p.325). The work of Szafran et al., (2016) was based on focus groups with five former young carers, the article reports that most participants had a negative experience of school and their caring role and this is supported throughout the article with quotes from participants. Questions could be raised about whether this was due to the small number of participants included in the study or due to issues relating to recall and they were remembering their circumstances as more extreme than the reality. Another general issue about engaging in research with former young carers concerned establishing accurately their age and level of schooling at the time discussed as there is no way of definitively assessing former young carers’ experiences or checking their educational timeline when such experiences occurred.

Using only professionals in research has the benefit of developing practice and identifying barriers from their perspective (Gray et al., 2008). However, it is only when these perspectives are combined with research involving those young people being impacted, that issues can be fully identified and addressed. The problem with not including young carers in such research is that only they can report about the caring role they are undertaking, how it impacts on them and how it makes them feel (Liegghio, 2015).

Small sample sizes can provide rich and deep insights but also have their own limitations. The majority of studies identified used twenty or less young carers in their samples (see Table 7). It has been cautioned that such small sample sizes “should not be seen as representative” but as giving more of an insight into the issues (Evans, 2011, p.344). In relation to the composition of samples, in those studies comparing young carers and young non-carers, it was noted that a disproportionate number of young carers and young non-carers were used particularly in the research of Warren (2007). Warren (2007) engaged three hundred and ninety young non-carers and twelve young carers (p.138). On a lesser scale, Pakenham and Bursnall (2006) had forty eight young carers to one hundred and forty five young non-carers and Pakenham et al., (2006) engaged with one hundred young carers and one hundred and forty five young non-carers, Sieh et al., (2013) used more young carers (one hundred and sixty-one) than

young non-carers (one hundred and twelve). Using a disproportionate mix of carers and non-carers in research has implications for making comparisons between the two groups. If a significantly smaller number of young carers are being used, generalisations cannot be drawn about young carers and the findings cannot be interpreted as the overall experience of young carers.

General sampling bias may naturally occur when recruiting young carers as research participants. Bjorgvinsdottir and Halldorsdottir (2014) commented that it is more likely that those young carers “who are more active, well-adjusted and responsible” would be chosen as participants; in the case they were discussing this choice was made by the parents of young carers (Bjorgvinsdottir and Halldorsdottir, 2014, p. 47). The idea was also presented by Cassidy and Giles (2013) that recruiting young carers through the organisations that help them is likely to exclude those young carers who are more disadvantaged.

Within the fifty peer reviewed articles identified as meeting the age inclusion criteria of the study it was common that no specific overall age breakdown of the young carers participating was given ⁶². In thirteen of the studies, although no specific overall age breakdown of the young carers was provided, an average age was given ⁶³. Alternatively, a generalised age bracket was given instead (Kavanaugh, 2014; Skovdal, 2011) or numbers of participants were placed under headings relating to their current level of education, for example, using category headings such as ‘Primary School’, ‘High School’, ‘Tertiary’ or ‘Currently Employed’ (Diaz et al., 2007; Pakenham et al., 2006; Pakenham and Bursnall, 2006). The work of Lewis and Meredith (1988) gave only general details of three quarters of their sample. It is also of note that no male and female breakdown was given regarding participants in seventeen out of the fifty studies identified ⁶⁴.

⁶² Javed et al., 2015; Lane et al., 2015; Nagl-Cupal et al., 2014; Pufall et al., 2014; Bjorgvinsdottir and Halldorsdottir, 2014; Cassidy and Giles, 2013; Fives et al., 2013; Sieh et al., 2013; Skovdal et al., 2013; Cluver et al., 2012; McAndrew et al., 2012; Evans, 2011; Skovdal, 2011; Smyth et al., 2011; Cooklin, 2010; Moore et al., 2009; Zhang et al., 2009; Hill et al., 2007; Warren, 2007; Martin, 2006; Pakenham et al., 2006; Pakenham and Bursnall, 2006; Robson 2006; Eley, 2004; Aldridge, 2003; Roche and Tucker, 2003; Thomas et al., 2003; Underdown, 2002; Banks et al., 2001; Gates and Lackey, 1998; Tatum and Tucker, 1998; ; Aldridge and Becker, 1993.

⁶³ Lane et al., 2015; Nagl-Cupal et al., 2014; Pufall et al., 2014; Cassidy and Giles, 2013; Fives et al., 2013; Sieh et al., 2013; Cluver et al., 2012; Zhang et al., 2009; Warren, 2007; Martin, 2006; Eley, 2004; Thomas et al., 2003; Gates and Lackey, 1998.

⁶⁴ Javed et al., 2015; Nagl-Cupal et al., 2014; Pufall et al., 2014; Heyman and Heyman, 2013; Sieh et al., 2013; Pufall et al., 2014; McAndrew et al., 2012; Smyth et al., 2011; Cooklin, 2010;

Although all the studies identified, at least, the age bracket relating to their young carer participants, the lack of information available on the exact age of young carers participating had implications on identifying results as relevant to the age criteria under study. Such information is also important as caring can impact on young people in ways that are specific to the age and life stage they are at. For example, in the work of Kavanaugh (2014) it is not possible to ascertain explicit figures from age sixteen plus, as the age category this falls into is fifteen to twenty years old. Similarly, Hamilton and Adamson (2013) provided the information that twenty-three participants were aged seven to seventeen, however it cannot be confirmed how many were aged sixteen and seventeen and therefore within the inclusion criteria. Javed et al., (2015) grouped young carers together in the age bracket of fifteen to twenty-four years old. In the instance of Manderson and McCune (2004), which reviewed the case notes of parents with children, the ages of children were depicted in the broad age brackets of zero to seventeen and nineteen to twenty eight, no reference was made to those aged eighteen and no other breakdown was given. One way of combating this problem was evidenced in the work of Evans (2011), Skovdal (2011), Moore et al., (2009), Zhang et al., (2009) and Martin (2006). These articles provided clarification by placing the ages of the young carer cited in brackets beside the relevant quotation. The failure of studies to provide information about the age breakdown of participants and whether those included in the sample are male or female limits how results can be analysed regarding any male/female specific trends being identified.

Several articles gave no details on the process/method they used to recruit participants for the research sample (Cooklin, 2010; Roche and Tucker 2003; Underdown, 2002; Banks et al., 2001; Coombes, 2001; Lewis and Meredith, 1988; Tatum and Tucker, 1998). It was also noted that in several articles no details were given as to how data collected had been analysed, for example, Fives et al., (2013), Evans (2011), Cooklin (2010), Martin (2006), Robson et al., (2006), Eley (2004), Roche and Tucker (2003), Tatum and Tucker (1998) and Aldridge and Becker (1993). The work of Underdown (2002) and Coombes (2001) did not contain information on the actual method used for conducting the study they based their articles on. Additionally, in the case of Underdown (2002), it is

Hill et al., 2007; Bauman et al., 2006; Robson et al., 2006; Aldridge, 2003; Roche and Tucker, 2003; Underdown, 2002; Banks et al., 2001; Aldridge and Becker, 1993.

unclear how many of the young carers, engaged at a weekend festival for one thousand two hundred young carers, were included in the research sample.

No details of ethical approval granted for the research were contained in twenty two articles ⁶⁵. This is regrettable given the ethical implications of collecting data from potentially vulnerable populations such as young carers. Further information would be of benefit for other researchers' submitting applications for ethical approval to research young carers.

It was identified that research findings were not always quantified. Statements would be made but would not be reinforced or evidenced by statistics, for example in relation to numbers of young carers reporting a particular problem or situation (Szafran et al., 2016; Bjorgvinsdottir and Halldorsdottir, 2014; Hamilton and Adamson, 2013; Evans, 2011; Skovdal, 2011; Smyth et al., 2011; Cooklin, 2010; Gray et al., 2010; Zhang et al., 2009; Warren, 2007; Martin, 2006; Eley, 2004; Banks et al., 2001; Gates and Lackey, 1998). Rather than quantifying numbers of young carers in results it was the practice of some researchers' to use general terms such as "most", "many", "more", "several" (Bjorgvinsdottir and Halldorsdottir, 2014; Eley, 2004). Another example of this was Gates and Lackey (1998) who made reference to "all participants" but who did not quantify statements, instead using phrases such as "for the most part" or "most of the youngsters" (Gates and Lackey, 1998, p.13). Although numbers of young carers were provided in some instances to support statements this was not done consistently (Thomas et al., 2003; Banks et al., 2001). Other researchers' used quotes as reinforcement for example Gray et al., (2010) and Zhang et al., (2009), presented tables of statistics regarding caring tasks being carried out (Smyth et al., 2011) or gave a breakdown of the themes present (Skovdal, 2011).

⁶⁵ Cassidy and Giles, 2013; Fives et al., 2013; McAndrew et al., 2012; Hill et al., 2011; Cooklin, 2010; Moore et al., 2009; Diaz et al., 2007; Warren, 2007; Martin, 2006; Pakenham and Bursnall, 2006; Robson et al., 2006; Eley, 2004; Manderson and McCune 2004; Roche and Tucker, 2003; Thomas et al., 2003; Underdown, 2002; Banks et al., 2001; Coombes, 2001; Gates and Lackey, 1998; Tatum and Tucker, 1998; Aldridge and Becker 1993; Lewis and Meredith, 1988.

3.2.3 Young carers and education

The literature presented strong contrasts in relation to young carers and their experiences of school, which is also evident in terms of the impact on their education. The positive and negative attitudes of young carers towards their education and their awareness of the importance of education on their future is also highlighted. These findings will now be outlined.

3.2.3.1 A mixed experience of school

School was reported by young carers to be a safe place; “a refuge” (Cluver et al., 2012, p.589), one of several “arenas of comfort” available to young carers (Evans, 2011, p. 351). School was also described as a form of respite (Smyth et al., 2011; Moore et al., 2009), “a break” and “a haven” with the school day being viewed by some as time they had to themselves free from their caring responsibilities (Lackey and Gates, 2001, p.324; Gates and Lackey, 1998, p.14). School was in effect viewed as “an escape” (Szafran et al., 2016, p.138), with others describing it as a “coping mechanism” (Cluver et al., 2012, p.594). As well as a place of respite, school was also seen as not just a place to be educated but an opportunity to be social, make friends and potentially meet other young carers (Cluver et al., 2012; Barry et al., 2011; Smyth et al., 2011; Moore et al., 2009). For some of those young carers unable to socialise outside of school because of their caring role “[t]he corollary of this was a feeling of boredom when away from school” (Fives et al., 2013, p.55).

For others, school was described as “a mixed blessing”, somewhere that they had a break from caring but which presented “its’ own set of problems” (Szafran et al., 2016, p.11). There was evidence of conflict between young carers and school (Thomas et al., 2003), with the claim being made that most young carers reported having “a negative school experience” (Szafran et al., 2016, p.12). School has also been described as a place that “could easily align itself with

insecurity” because young carers feel unsupported and/or experienced bullying (McAndrew et al., 2012, p.16).

3.2.3.2 Young carers and attitudes to education

Smyth et al., (2011), Eley (2004) and Thomas et al., (2003) identified a positive attitude from young carers in relation to education, that they wanted to do well even when faced with problems and a lack of support. Thomas et al., (2003, p.40) wrote that they were “struck” by young carers and their “conscientious attitude” towards education and the level of awareness they had of how it was important for them to do well. Eley (2004, p.69) reported that female young carers participating in their research “expressed a consensual resilience- ‘nothing is going to hinder me’” type attitude even when perceiving a lack of support at school to help them. In contrast, the research of Barry et al., (2011) identified that female respondents were more likely to be negative about school and teachers. Both of these studies were based in GB using Scottish participants (Barry et al., 2011; Eley, 2004). With such differing perspectives evident in existing research, it is clear that this is an area that warrants greater research attention. In Africa, a number of young carers were recorded as feeling proud of their school attendance and achievements (Cluver et al., 2012). Overall, the young carers in this study expressed the perception “of their own education as vitally important in improving their lives and those of their families” (Cluver et al., 2012, 593).

3.2.3.3 Degrees of impact

Young carers' experiences of school and the impact upon their education are considered to be dependent on both the condition of the person they are caring for and his/her health and well-being at that particular time (Smyth et al., 2011). Smyth et al., (2011) do not quantify the extent of impact but reports that some young carers experienced "little impact" on their education, yet for others it was having a "heavy toll" (Smyth et al., 2011, p.512-513). The interpretation of the impact on a young carer's education being either "little" or "heavy" is evidenced throughout the literature on the subject (Smyth et al., 2011, p.512-513).

Other research found that having a caring role was not overly impacting on the majority of young carers' education, in fact some young carers were noted as doing well at school (Fives et al., 2013; Bjorgvinsdottir and Halldorsdottir, 2014). Bjorgvinsdottir and Halldorsdottir (2014) reported that some participants were excelling at school. The example was given of one young carer who equated being an overachiever with the fact they viewed school as an escape (Szafran et al., 2016). Eley (2004) found that young carers generally reported their school work was not "suffering unduly" because of their caring role, in these cases young carers outlined "their organization of caring in balance with schooling" (Eley, 2004, p.69). In the research of Banks et al., (2001) a similar pattern of managing "to cope with their schoolwork" theme was displayed by "most young people" (Banks et al., 2001, p.809-810). Nagl-Cupal et al., (2014) found little difference between young carers and young non-carers in relation to school, 75.8% of young carers compared to 78.1% of young non-carers described themselves as a "successful student" and 3.0% of young carers compared to 3.1% of young non-carers said that they "have no time for school" (Nagl-Cupal et al., 2014, p.2321).

In contrast, the work of Szafran et al., (2016), Kavanaugh (2014), Sieh et al., (2013); Diaz et al., (2007) and Thomas et al., (2003) showed the caring role as having a heavier toll on young carers' education. It was commented by Szafran et al., (2016) that former young carers reported obtaining what they described as "poor grades" (p.138). Kavanaugh (2014) reported that amongst those caring for a parent with Huntington's disease, "frequency of caregiving is correlated with higher conflict with the ill parent and more problems at school" (p.683). Young

carers experiencing problems at school for this reason was in turn “significantly correlated with higher depression scores” (Ibid). Sieh et al., (2013) examined differences between one hundred and sixty-one young people with a chronically ill parent with one hundred and twelve young people with healthy parents. They found those young people with a chronically ill parent scored higher on the frequency of caregiving responsibilities and household chores (Sieh et al., 2013). This same group also had a worse grade point average than the control group, with 2.8% more young carers having failed at least one school year (Sieh et al., 2013). Thirty seven percent or two hundred and twenty-five participants in the research of Diaz et al., (2007) identified young caregivers as selecting “agreed or strongly agreed” in response to the statement that *their caregiving situation hinders their learning* (Diaz et al., 2007, p.136). Thomas et al., (2003) reported that half of their participants “appeared to be struggling” at school with homework and keeping up with their school work in general (Thomas et al., 2003, p.5). Research in Tanzania and Zimbabwe highlighted females as more likely to have their education impacted on than males (Robson et al., 2006).

3.2.4 How caring impacts on a young carer’s education

Young people having a caring role is evidenced as impacting on their education in various, often interconnected ways, and to different degrees of impact. The problems experienced by some young carers in education are well documented by researchers’ and can be grouped into the following themes; lack of recognition, support and understanding; having an adult role at home and being a child in school; confidentiality and intrusiveness; caring role as the priority; concentration and tiredness; homework and extracurricular activities; absence and lateness; dropping out; young carers and their future; poverty and hunger and bullying, stigma and isolation.

Such problems have been described by Roche and Tucker (2003), as leading to “lost educational opportunities” for example in relation to those young carers experiencing absenteeism and concentration problems (Roche and Tucker,

2003, p.445). The “negative educational impacts” have been linked to young carers’ “poorer long-term educational outcomes” (Cluver et al., 2012, p.599). These themes will now be discussed individually.

3.2.4.1 Lack of recognition, support and understanding

The lack of recognition, support and understanding in schools was highlighted in research projects carried out in Australia (Hamilton and Adamson, 2013; Smyth et al., 2011), Canada (Szafran et al., 2016), Iceland (Bjorgvinsdottir and Halldorsdottir, 2014) and GB (Heyman and Heyman, 2013; Barry et al., 2011; Eley, 2004; Roche and Tucker, 2003; Thomas et al., 2003; Underdown, 2002).

In the Australian context, Smyth et al., (2011) disclosed that young carers had inconsistent experiences regarding the support and understanding they received from school. They reported that many participants in their study said teachers were aware of their caring role and “in most cases” they did feel supported; others reported feeling disappointed at the lack of support and understanding that they received (Smyth et al., 2011, p.513). Hamilton and Adamson (2013) also noted concern about the lack of support and understanding experienced by young carers from the school system.

It was reported that for some former young carers in Canada and some young carers in Iceland, not only did they not receive support in school, they felt teachers were aware of their situation but chose to ignore it, highlighting that recognition of their role did not guarantee understanding and support (Szafran et al., 2016; Bjorgvinsdottir and Halldorsdottir, 2014). Szafran et al., (2016) recorded that former young carers had felt their teachers knew or suspected something but did not know how to deal with it and as a result “ignored their suffering and just let things slide” (p.139). Bjorgvinsdottir and Halldorsdottir (2014) reported that young carers were “taught but not supported in school” (p.43). Most participants of this research did not recall receiving “any formal support”, even when teachers were aware of their situations it was claimed that no attempt was made to talk to the young person about the problems they were facing (Bjorgvinsdottir and Halldorsdottir, 2014, p.43). The importance of young carers wanting to discuss

their caring role with their teacher was highlighted in the research of Bjorgvinsdottir and Halldorsdottir (2014), although in the context of their research this was an opportunity they did not feel they had received. This raises questions about teacher training and the ethos of schools when dealing with pastorally sensitive issues.

In GB, one study identified “a few” young carers who felt that their school had “sufficient understanding of their situation (Underdown, 2002, p.58). Other studies in GB would suggest a significant need for schools to address the lack of recognition, support and understanding being shown by them towards young carers. Eley (2004) reported young carers felt there was a need for schools to be more proactive to support them “through systems of pastoral care”, without which they felt that “some young carers could slip through the net” (p.71). Some felt that professionals needed to be more aware of the facts of being a young carer and female participants in this study thought teachers were in prime position to quickly identify young carers and support them (Eley, 2004).

The research of Thomas et al., (2003) emphasised the lack of recognition and awareness schools had about young carers. This study contacted three hundred schools to recruit young carers for their study, three schools responded, two of which answered that their school had no young carers. Thomas et al., (2003) suggested that this indicated “a marked lack of awareness of young carers among the professionals who might be best placed to identify them” (p.39).

Echoing Canadian and Icelandic research, Thomas et al., (2003) commented that the young carers they met had different experiences of school and that staff awareness of the situation did not guarantee that the school would be supportive. The main criticisms from young carers in the research of Barry et al., (2011) was “at the attitude of teachers rather than the quality of education” referring specifically to teachers not being supportive of those who were behind with their work and needed encouragement (p.531). Comments made about teachers and school in this piece of research were described as “generally more negative than positive” (Barry et al., 2011, p.531). It was suggested by the authors that the reason behind teachers’ actions could be that they were “not adept at understanding” or “not given the discretion to accommodate the needs of young carers” (Barry et al., 2011, p.532). Some participants did however speak of a

specific teacher who was aware of their situation and was supportive, understanding and flexible with deadlines to accommodate the young person should a situation arise at home that meant they should need it.

Heyman and Heyman (2013) and Roche and Tucker (2003), gave examples of schools having less successful or misguided strategies to adequately address the needs of young carers. Heyman and Heyman (2013) described how a young carer was supported in school using “positive discrimination” (p.570). This was a well-intended but misguided approach to support this young carer but could be used to evidence a need for greater understanding and awareness about young carers and the identification of other methods of support for young carers. Roche and Tucker (2003) outlined similarities between being a young carer and a young person with ME, explaining both groups of children experienced no understanding and some disbelief about their situation from school staff (p.446-450). They highlighted that young carers can be treated from a “school phobic perspective” where their absence from school was “reinterpreted as an act of deviance” or as the “manifestation” of other problems unrelated to their caring role (Roche and Tucker, 2003, p.450).

3.2.4.2 An adult role at home and a child in school

Some young carers in GB (Heyman and Heyman, 2013; Barry et al., 2011; Cooklin, 2010) and Zimbabwe (Martin, 2006) reported having difficulties dealing with their dual identity as an adult role at home and a carer yet treated as a child/pupil at school. Cooklin (2010) commented in his study that such contradictory expectations were cause for complaint by young carers. An example of the impact of such contradictory expectations was given by Heyman and Heyman (2013, p.575) of a young carer who “considered that his need to combine caring and educational roles was not well handled by [teaching] staff”. His perception was attributed to having caring responsibilities from an early age, which had “made him more sensitive than others in transition between childhood and adulthood to inconsistencies in age-related societal expectations” (Heyman and Heyman, 2013, p.575). Unlike the studies of Heyman and Heyman (2013) and Cooklin (2010), Martins’ (2006) Zimbabwean study comments on this issue from a different context showed how cultural difference can impact on a young carer’s education. They describe young carers as school pupils being expected to “behave in an accepted way...irrespective of taxing duties at home, fulfilling the role of school child”, with teachers and other pupils being unaware of their role at home (p.116).

3.2.4.3 School, confidentiality and intrusiveness

There exists conflicting and somewhat contradictory evidence in relation to whether young carers wanted their school to be informed about their caring role. All studies highlighting this issue were based in GB.

Several young carers (no specific figures given) did not want school to know about their caring role as they wanted to keep home and school life separate, and were wary of what could potentially happen should a teacher know more about their situation (Barry et al., 2011). Barry et al., (2011) outlined young carers as being unsure about “confiding in teachers about problems”, because they felt

“teachers could not be trusted in the same way as a ‘neutral’ friend could to ‘keep a secret’” (p.533). On a different note, the majority of participants in the study of Banks et al., (2001) were reported as not being concerned about their situation and “denied they felt the need to talk to anyone about it” (p.806).

Other young carers felt teachers needed to be more aware of their “exceptional circumstances” but “not intrude upon their family matters within the school setting” or break confidentiality (Eley, 2004, p.70). Whilst being criticised for not supporting young carers, schools also faced criticism for being “over intrusive” and “trying too hard” (Thomas et al., 2003, p.39). In their study, Thomas et al., (2003) cited a young carer whose father was in hospital and who experienced questions “in every class I went to”, saying “it sort of tires you out in the end” (p.39).

3.2.4.4 Caring as the priority- a balancing act

Some young carers in Australia, Ireland and GB reported their caring role took precedence over their education (Hamilton and Adamson, 2013; Fives et al., 2013; Thomas et al., 2003). Hamilton and Adamson (2013) noted most of the young carers and young adult carers involved in their research said that “caring was their priority” (p.107). To illustrate, Fives et al., (2013) gave the example of a sixteen-year-old girl who is the primary carer of three siblings and a father who all have care needs. Should there be a “care-related crisis in the household” she told researchers’ she would leave school immediately “to address the problem herself as school would be the last thing” (p.55).

A number of young carers in Australia and GB likened their caring role and attending school to a balancing act (Hamilton and Adamson, 2013; Heyman and Heyman, 2013; Evans, 2011; Thomas et al., 2003). Young carers described “fitting their school work around their caring responsibilities” (Evans, 2011, p.350). One young carer likened their life to being “like a set of scales” (Barry et al., 2011, p.530). Other young adult carers aged between eighteen and twenty-four were described as “expressing particular frustration with the challenge of

balancing further education and caring tasks” (Hamilton and Adamson, 2013, p.107).

3.2.4.5 Concentration and tiredness

Concentration problems at school due to their caring role was reported by young carers in studies based in Australia (Smyth et al., 2011; Pakenham and Bursnall, 2006), Canada (Szafran et al., 2016), Ireland (Fives et al., 2013) and GB (Evans, 2011, p.350; Aldridge, 2003). Some young carers disclosed that while they were at their place of education they felt distracted, either out of concern and/or worry for their cared person at home, or they were preoccupied thinking about that person’s needs (Fives et al., 2013; Evans, 2011; Smyth et al., 2011; Pakenham and Bursnall, 2006; Aldridge, 2003). Aldridge (2003) gave the example of one young carer who worried throughout the day that his parent may have been admitted to hospital while he was at school. This type of worry and anxiety was offered as an explanation by Sieh et al., (2013) regarding the lower levels of academic achievement evidenced by young carers in their study:

“lower academic achievement is mediated by elevated levels of anxiety...so especially children with preoccupations and anxieties concerning their parents illness perform worse at school” (p.216).

Some young carers equated their concentration problems with tiredness (Evans, 2011). Tiredness was also identified as having health implications for young carers, which in turn could have more serious implications for their education (Banks et al., 2001). Young carers experiencing tiredness at school because of their caring role was highlighted by Szafran et al., (2016), Evans (2011), Smyth et al., (2011), Eley (2004) and Banks et al., (2001). Smyth et al., (2011) recorded that some young carers associated their tiredness with having to stay up late to complete homework once their caring tasks and household chores were finished. Instances of young carers being so tired they actually fell asleep in school were evidenced in the work of Szafran et al., (2016), Eley (2004) and Banks et al., (2001). Eley (2004) provided the example of one young carer saying they “always felt run down” and another disclosing that they had gone to sleep in school toilets

after they had been up during the night looking after a parent (p.69). Young carers reporting falling asleep in school are in low single figures in the instances where they have been quantified (Eley, 2004; Banks et al., 2001).

3.2.4.6 Homework and extracurricular activities

In Africa, Australia, Austria, Canada and the USA, some young carers were recorded as experiencing varying degrees of problems in relation to completing their homework. These ranged from young carers saying they had no time to study, to others who claimed caring interfered more with their social life than with their homework (Nagl-Cupal et al., 2014; Bauman and et, 2006). Bauman et al., (2006) reported a more frequent occurrence in their study of young carers reporting their caring role and other responsibilities within the home “interfered with spending time with friends and in after-school activities but less often with homework” (p.68). The proportion of young carers revealing problems completing homework ranged from “many” to a “minority” (no specific figures given by research) (Smyth et al., 2011; Robson et al., 2006; Banks et al., 2001; Lackey and Gates, 2001).

Smyth et al., (2011) commented that finding the time to complete homework and other assignments was “a challenge for many of the young people” involved in their research (p.513). This, alongside forgetting or failing to complete assignments and feeling short of time, were described as “common complaints” from participants (Ibid, p.513). Former young carers have recalled “not having their homework done” (Szafran et al., 2016, p.138). In contrast, homework problems were evidenced in a small minority of cases by Robson et al., (2006).

The frequency of how often homework is impacted by a caring role is something that was only touched upon in the results from Nagl-Cupal et al., (2014), Bauman et al., (2006), Thomas et al., (2003) and Lackey and Gates (2001). In a study comparing young carers with young non-carers, 30.2% of young carers compared to 22.8% of young non-carers said they had no time to study, implying it was a continual problem (Nagl-Cupal et al., 2014). Thomas et al., (2003) reported for some young carers “caring tasks frequently took precedence over

homework” (p. 40). In contrast, Bauman et al., (2006) reported that 16% of young carers from their New York sample and 52% of young carers from their Mutare sample stated that “once in a while” they were unable to do homework because chores interfered (p. 65). Lackey and Gates (2001) found that young carers typically had increasingly less time for homework as they progressed through school.

Often within the literature the challenge for young carers to complete homework was reported alongside their inability to take part in extra-curricular activities (Szafran et al., 2016; Bauman et al., 2006; Lackey and Gates, 2001). As was the case in relation to time available for homework, Lackey and Gates (2001) revealed that as young carers progressed through school, they reported having less time for extra-curricular activities. Other young carers and former young carers reported missing out on extra-curricular activities (Szafran et al., 2016; Moore et al., 2009). Moore et al., (2009) discovered two thirds of their participants said they were not able to participate in after-school activities because of their caring role. This same research revealed some of the young carers in their sample were unable to afford to participate in extra-curricular activities.

3.2.4.7 Absenteeism and lateness

Young carers absenteeism from school is a key focus in the literature (Szafran et al., 2016; Lane et al., 2015; Pufall et al., 2014; Fives et al., 2013; Cluver et al., 2012; Evans, 2011; Skovdal, 2011; Smyth et al., 2011; Moore et al., 2009; Zhang et al., 2009; Pakenham and Bursnall, 2006; Roche and Tucker, 2003; Thomas et al., 2003; Lackey and Gates, 2001). Taking time off school was described as one strategy used by young carers “to manage caring demands” (Smyth et al., 2011, p.513). Thomas et al., (2003) emphasised there was the feeling amongst young carers that they really wanted to go to school and were concerned when unable to attend: “[t]runcy was not an issue; they wanted to go to school, and seemed genuinely concerned when they had to be absent or were unable to do their work” (p.40). Linking to this, Lackey and Gates (2001) reported that “‘missing classes or special events’ became more upsetting in the high school years” (p.324).

Roche and Tucker (2003) highlighted some young carers' comments that "the pressure to not attend school becomes that much greater the longer they are away" (Roche and Tucker, 2003, p.450). These young carers outlined how returning to school after a period off involved an explanation about their absence and catching up on work, and that this mixed with the thought their teachers did not care about their situations made returning to school difficult (Roche and Tucker, 2003). One young carer is quoted as saying because of this "[t]he situation becomes impossible, so you just stay away" (p.450).

Research reveals variations in the levels of absenteeism experienced by young carers. Specific statistics on this subject were presented by Lane et al., (2015) and Moore et al., (2009). Two thirds of participants in Lane et al.'s (2015) South African study were attending school regularly and one third reported "missing some school" (p.58). Half of participants in an Australian study reported that their school attendance was affected by caring for someone, with young carers claiming, "they were needed at home to help care for their relative" (Moore et al., 2009, p.10).

There was some variation between the experience of young carers participating in studies carried out in GB and Ireland and those in African, Australian, Canadian and Chinese studies, which will now be outlined.

Within GB and Ireland, young carers were identified as being more likely to be absent from school but in reality, this was not the experience being expressed by the majority of young carers. Data produced by Warren (2007) revealed that although young carers were more likely to miss school or be late to school because of caring responsibilities "a large majority of young carers" were not absent from school and were most likely to arrive on time (p.142). Research carried out in England found that, "several young carers" felt their attendance was affected in some way by their caring role "during a period of parental illness", with such absences ranging from days to one young carer declaring an absence of several months (Evans, 2011, p.350). Young carers in an Irish Study outlined "they were absent from school whenever there were care-related concerns at home" (Fives et al., 2013, p.55).

In contrast, African studies identified a more significant impact on young carers' school attendance and a link with this to cultural practices and expectations

regarding caregiving. Lane et al., (2015) reported one third of their sample had missed some school because of their caring role. Research with Zimbabwean young carers showed that they were “less likely to attend regularly than their unaffected peers”, with this same group of young people also considered not as likely to attend secondary school (Pufall et al., 2014, p.6). For some young carers who managed to go to school alongside providing care, this was attributed “to the presence of other adults in the house” (Robson et al., 2006, p.18). Late arrival amongst young carers was also identified (Robson et al., 2006).

In Kenya, research identified the potentially erratic educational experience for some young carers due to the practice of sending a young person away to care for someone, uprooting them from their education (Skovdal, 2011). Although many of these young people had the opportunity to continue their education in the new location “many did not and therefore had an involuntary break from school” (p.1266). The involuntary nature of absence for some young people is reiterated in the research of Lane et al., (2015) and Cluver et al., (2012). Missing school was described as a “forced choice” with young carers feeling morally obliged to provide care above anything else (Cluver et al., 2012, p.590). Some young carers were described as “the children who unhappily missed classes or left university to care for ill family members” (Lane et al., 2015, p.63). The link between care provision and gender was identified by Skovdal (2011) who described this as the “sociocultural gendered constructions of care”(p.1266). An example given to illustrate this was of a girl who was not in secondary school, (attending secondary school is described as “an investment”), had previous caring experience and was automatically sent away (Skovdal, 2011, p.1266).

In rural China, Zhang et al., (2009) termed the phrase “suboptimal schooling” in relation to the young carers they researched (p.547). Whilst some experienced long-term absence and others reported dropping out, for those remaining in school, often their schoolwork was affected by their caring role (Ibid). The impact of these experiences on future opportunities, linked to the fact that participants lived in “an already impoverished rural area” and the competitive nature of China’s education system, was described as limiting their future opportunities by the “deprivation of educational opportunities at an early age” (Zhang et al., 2009, p.548).

Like Africa and China, problems with school attendance were also evidenced in Canadian and Australian studies. In Canada, former young carers “generally recalled missing a lot of school” (Szafran et al., 2016, p.138). In Australia, as previously mentioned, half of participants said their school attendance was affected by their caring role (Moore, et al., 2009).

3.2.4.8 Dropping out

A caring role was mentioned in several articles as leading to small numbers of young carers dropping out of education (Cluver et al., 2012; Zhang et al., 2009; Robson et al., 2006; Thomas et al., 2003; Lackey and Gates, 2001). This was evidenced in studies carried out in China (Zhang et al., 2009), Iceland (Bjorgvinsdottir and Halldorsdottir, 2014), Africa (Lane et al., 2015; Cluver et al., 2012; Robson et al., 2006), USA (Lackey and Gates, 2001) and GB (Thomas et al., 2003). For those young carers dropping out because of their caring role, Robson et al., (2006) expressed concern that for some young carers “their formal education was sacrificed, they had stopped attending school and their future was being determined by the outcome of their imposed caring responsibilities” (p.26). The long term impact of young carers dropping out of school, (as well as being absent from school), is described as being extensively evidenced as “associated with lower chances of completing basic schooling” which in turn “lead[s] to lower socio-economic status as adults” (Cluver et al., 2012, p.599).

Zhang et al., (2009) and Robson et al., (2003) indicated the number of young carers dropping out due to caregiving were small. Numbers of young carers dropping out because of their caring role were more specifically outlined in the work of Lane et al., (2015), Cluver et al., (2012), Thomas et al., (2003) and Lackey and Gates (2001). Cluver et al., (2012) mention 2.0% of participants caring for someone with HIV saying they were missing or had dropped out of school. Eight young carers, or 2.3% of the sample participants in the research of Lane et al., (2015), had dropped out of school. Two young carers disclosed leaving school because of their caring role in the work of Thomas et al., (2003); however, both hoped to return to education as soon as they could. Lackey and Gates (2001)

revealed four former carers said they had left high school because of their caring role (Lackey and Gates, 2001). Bjorgvinsdottir and Halldorsdottir (2014) identified young carers with learning difficulties as dropping out of school earlier than expected due to not having enough support at school and having to maintain their caring role at home.

3.2.4.9 Young carers and their future

Studies carried out in Australia, GB and the United States of America presented findings relating to young carers and their futures, all reported similar findings (Hamilton and Adamson, 2013; Heyman and Heyman, 2013; Smyth et al., 2011; Warren, 2007; Lackey and Gates, 2001; Tatum and Tucker, 1998; Lewis and Meredith, 1988).

Young carers are recorded as wanting to continue their education but have concerns about doing so, for example young carers participating in the research of Smyth et al., (2011). Here, many were described as “highly motivated students” who wanted to continue their education and discussed their future plans, with some also expressing concerns “as to whether they would encounter constraints on realising their aspirations” (p.513).

Warren (2007) wrote: “one of the most poignant findings” of their research was the perceptions young carers held on how their caring role would impact on their future and the economic and social elements that may limit their choices. Such perceptions, they stated, appeared to be realistic “both with regards to their future material disadvantage and its impact on their access to continuing education” (p.143). Compared to young people with no caring responsibilities, young carers in this study were identified as “more likely to identify barriers that might prevent them from fulfilling their future ambitions” (p.143), and a lack of qualifications was recognised as a significant barrier to their future plans.

Heyman and Heyman (2013) commented that the young carers they interviewed saw themselves as “competent navigators of their own future” and had “no awareness that they were regarded as vulnerable” by professionals (p.576). This

contrasted with all but one of the professionals interviewed in this research who had “constructed being a young carer in terms of risk to their personal and vocational future well-being” (p.569).

Hamilton and Adamson (2013) highlighted differing perspectives between young carers and young adult carers on “the effects of caring on future aspirations” (p.114-115). The closer those young people with a caring role approached “important life course transitions” such as leaving home, starting their career or entering third level education the more constrained they felt by their caring responsibilities (Ibid, p.105). Younger carers were described as expressing “a much greater sense of possibility in their plans for tertiary education” (Ibid, p.108). In contrast “a sense of constrained possibility was particularly pronounced for young adult carers who were at the stage of making real decisions about tertiary education” (Ibid).

Examples of how their caring role has impacted on young peoples’ decisions about education have been documented in relation to leaving home, choice of university, course, hours of study and career choices. Leaving home was problematic for some young carers, which had potential to limit their future education choices (Warren, 2007; Tatum and Tucker, 1998). Early research by Tatum and Tucker (1998) discussed the influence of caring on future life chances. They reported many of the young people interviewed “feeling trapped” and that they would be abandoning the person they were caring for if they left the family home (Tatum and Tucker, 1998, p.24-25). Data collected by Warren (2007) also showed that many young carers chose to continue living at home when they left school and that they were “more likely to experience ambivalence about where they will live in the future” (p.143). Caring has been linked to impacting on the practical decisions young carers make about their education (Hamilton and Adamson, 2013). Hamilton and Adamson (2013) compared the future aspirations of young carers and young adult carers. For both groups, it was concluded that caring was not affecting their ambitions for the future, rather it impacted on the location of the place of study, type of course and hours of study that they chose. Some young carers in third level education were noted by Hamilton and Adamson (2013) as finding this level of education more flexible to their caring role. When it comes to choosing a career pathway, former young carers agreed their caring role influenced their career choices (Lackey and Gates, 2001). It was noted by

Lewis and Meredith (1988) however that the career progression of former female young carers had been “particularly likely to suffer from her lack of flexibility and mobility” (p.11).

3.2.4.10 Poverty and hunger

Research projects in Africa, Australia and Canada provided details of poverty experienced by young carers and the impact this was having on their education (Lane et al., 2015; Liegghio, 2015; Cluver et al., 2012; Moore et al., 2009). Implications of poverty ranged from young carers being unable attend school because they were unable to pay school fees (Africa), young carers experiencing lower academic achievement (Canada) and young carers being unable to afford the basic equipment they were required to bring to school with them and to participate in extracurricular activities (Australia).

In African studies, a strong link between poverty and struggling to afford school fees was evidenced. This illustrated the interconnected nature of the problem’s young carers face; should a young carer and their family be unable to afford school fees, this can lead to dropping out of school, impacting on future life chances and increasing the likelihood of isolation. A small number of young carers in Africa were reported by Cluver et al., (2012) as being “unable to continue schooling due to extreme poverty” (p.591). Martin (2006) identified situations where a child was the primary carer, the family was living in poverty and some were unable to attend school because they could not pay school fees. Lane et al., (2015) described coming across a small number of young carers who “were observed cleaning sheep heads (‘smiley’) and shin for sale in order to raise money for school fees” (p.60). The introduction of “no fees schools in high deprivation areas” in 2006 had made school more accessible for those who would otherwise be unable to afford school fees, however this did not address the problem for those young carers unable to afford transport costs to their place of education (Cluver et al., 2012).

In Canada, Liegghio (2015) focused primarily on young carers, poverty and the link to academic achievement. Moore et al., (2009) described this as “a significant issue for many young carers” in their Australian based sample as it “often restricted their capacity to participate fully in their education” (p.11). In their study, this manifested itself in young carers being unable to afford “basic school requirements” such as uniform, stationery, textbooks and transport, as well as being unable to afford participating in extracurricular activities (Ibid).

The issue of young carers experiencing hunger at school was raised by Szafran et al., (2016) and Cluver et al., (2012). In their South African study, Cluver et al., (2012) identified young carers feeling hungry at school because of poverty as a major theme of their research and twenty-two per cent of participants caring for someone with AIDs reported feeling “constantly hungry” at school (p.591). Cluver et al., (2012) also linked the impact of hunger on cognitive development and to “poorer academic performance” (p.599). Szafran et al., (2016) found that former young carers in Canada had experienced hunger at school.

3.2.4.11 Bullying, stigma and isolation

Young carers experiencing bullying at school was recorded in GB based studies (McAndrew et al., 2012; Barry et al., 2011; Evans, 2011; Cooklin, 2010; Warren, 2007; Gray et al., 2008; Banks et al., 2001), alongside other studies based in Australia (Moore et al., 2009), Canada (Szafran et al., 2016), and South Africa (Cluver et al., 2012).

Reasons attributed to the bullying experienced by young carers have been linked to the young person’s caring role, the medical condition of the cared for relative, or the general perception that the young person is different (Cluver et al., 2012; Evans 2011; Warren, 2007; Banks et al., 2001). Young carers are reported as fearful of bullying in both a school and neighbourhood context (Cooklin, 2010). In school, young carers felt that teachers and fellow pupils could do more to support them with the bullying they faced (McAndrew et al., 2012). McAndrew et al., (2012) commented that for those young carers bullied at school, often “they are

not able to rely on their parents for support in dealing with it” which in turn heightens their vulnerability in such situations (p.16). One extreme consequence of bullying was described by a former young carer who stated they left school because of bullying and were then home schooled (Szafran et al., 2016). It should be noted that it was not explicitly confirmed that the bullying they experienced was linked to them being a young carer.

In terms of numbers of young carers reporting bullying, Moore et al., (2009) found this was the case amongst 45.0% of their participants. Warren (2007) identified young carers as more likely than children with no caring role to report bullying “because of the help they give at home” (p.142). A link has been suggested between gender and experiences of bullying; female respondents were reported as being more likely to be “affected” by bullying at school in general, not just when providing a caring role (Barry et al., 2011, p.531).

Underdown (2002) reported that many young carers felt “stigmatised and isolated” (p.58). This idea of “stigma” in the literature had various meanings for different young carers. Some linked stigma to the illness of the person they were providing care for (Cluver et al., 2012; Evans, 2011). For example, caring for someone with HIV/AIDS was identified as a reason why a young person would not share their caring role with classmates and teachers (Evans, 2011). Others reported feeling stigmatised in that they were deemed “problem children” when they had not completed their homework because of their caring role (Underdown, 2002, p.58). Most participants in the research of Aldridge et al., (1993) described lateness and absenteeism from school leading to embarrassing explanations for them in class in front of peers (Aldridge and Becker, 1993). Others linked stigma to accepting help from others; Cluver et al., (2012) identified what they described as the “complex dynamics of peer support and peer stigma at school” (p.589). Researching in South Africa they commented that for some young carers “accepting support from peers was directly connected to increased stigmatization”, for example jokes being made about their family situation (p.594).

In some instances, stigmatisation could lead to social exclusion and further isolation in studies carried out in Australia, Norway and GB (Torp et al., 2013; Gray et al., 2010; Moore et al., 2009; Gray et al., 2008; Roche and Tucker, 2003; Tatum and Tucker, 1998). Fifty one percent of participants in an Australian study

reported they found it difficult to make and maintain friendships, with “many” saying this was because of their caring role and that they felt isolated (Moore et al., 2009, p.11). Young carers in this study also mentioned they found it “difficult to relate to other young people” and accepting support when times were hard (Ibid). Sixty-five per cent of participants described “their relationships with others at school” as “strained” (p.10). A number of reasons were given for this; problems getting to school, poverty, no time for socialising after school, difficulty “engaging with others who understand”, bullying, not feeling safe or comfortable and having negative emotions such as anger (Moore et al., 2009, p.10). Relating to this, Tatum and Tucker (1998) also noted that being unable to be involved in after-school activities and clubs, added to the social exclusion of being a carer.

Young carers’ isolation and difficulty relating to their peers has been described as problematic for two reasons (Moore et al., 2009). Firstly, there are “causal links between a young person’s participation in education and their educational achievements”: in other words, if a young carer feels a sense of belonging they are more likely to achieve academically; secondly, because “school connectedness plays an important role in young people’s ability to cope with life challenges and events” (p.16). School is a place for young people to “gain support from friends” (p.16)), which is significant as it is documented in times of stress, young people are “less likely to engage with their parents or other adults” and “most likely to seek support from their friends” (p.17). The importance of social interaction and having friendships was also highlighted in the research of Torp et al., (2013), with several young carers identifying friends as beneficial to their mental health. These young carers “emphasised the necessity and importance of simply being with their friends and maintaining a normal life” (p.303).

3.2.5 Recommendations

Recommendations identified in the literature to address the needs of young carers/young adult carers in education focused on; working with young carers to formulate policy, practice and guidance; early intervention, recognition, awareness, understanding, emotional and practical support, confidentiality, flexibility, the identification of key staff, utilising young carers organisations in schools and young carer specific policies and support services for young carers and their families.

Importantly it was recommended that young carers should be involved in developing any policies, practices and guidance to help meet their educational needs, as they are “best placed” to inform those who educate them about how they can be identified and supported (McAndrew et al., 2012, p.17; Warren, 2007, p.144).

Early intervention is recommended as having “potential to reduce the cumulative effects of those daily constraints over time on young carers’ sense of future possibility” (Hamilton and Adamson, 2013, p.115). Hamilton and Adamson (2013) commented that although it is unlikely to eliminate the effects of a caring role it may “reduce the bounded sense of possibility” they witnessed in their study (p.115).

The school environment must be recognised and utilised as being of enormous significance and importance in the identification and support of young carers. Bjorgvinsdottir and Halldorsdottir (2014) recognised that while schools have a significant role in shaping a young person’s “self-perception and personal confidence”, they may not make “the necessary effort to meet the educational and emotional needs of children burdened with caring responsibilities” (p.45). Young people spend the majority of their time at home and at school (Stamatopoulos, 2015; Kavanaugh, 2014; Gray et al., 2008; Warren, 2007, Thomas et al., 2003), therefore teachers, pastoral staff, Educational Welfare Officers and School Nurses are “well placed” to identify and provide support to young carers (Warren, 2007, p.144; Thomas et al., 2003, p. 45; Coombes, 2001).

Being at the forefront, Warren (2007) writes that they “have a clear role to play in the early identification of young carers” (p.144).

To utilise the effectiveness of schools’ and other places of education to identify and support young carers, awareness-raising amongst staff would help them recognise the signs that a young person had a caring role and promote understanding. (Stamatopoulos, 2015; McAndrew et al., 2012; Smyth et al., 2011; Gray et al., 2008; Warren, 2007; Underdown, 2002). The ability of teachers, pastoral staff, Educational Welfare Officers and School Nurses to identify and support young carers is ultimately dependent on their level of awareness about young carers and their understanding about the issues they face. These elements could be addressed via awareness raising/teacher training. An example of what a session could include would be how to recognise behavioural indicators typical of young carers in education such as lateness, being absent, concentration problems, withdrawing from others and in some cases behavioural difficulties (Thomas et al., 2003; Warren, 2007).

Complementing awareness-raising on the issue of young carers, education professionals need to be equipped with the knowledge and skills of how they can support a young carer, be this practically, emotionally or knowing where to signpost or refer them to (McAndrew et al., 2012; Thomas et al., 2003; Underdown, 2002). Underpinning all methods of support, young carers wanted recognition and understanding by teachers and schools about their caring responsibilities (Smyth et al., 2011; Underdown, 2002). They also wanted their confidentiality to be respected and to keep their home life private in their place of education from those who do not need to know (Underdown, 2002). Linked to recognition, understanding and confidentiality, the need to increase sensitivity in relation to how young carers are treated within the education system has been identified (Heyman and Heyman, 2013), particularly in relation to how young carers are treated as adults within their home environments as carers, yet treated as children in school (Ibid).

Many practical support methods are recommended in the literature to help young carers in education; allowing access to a telephone to check on home (Underdown, 2002), homework clubs (Underdown, 2002), study support (Warren, 2007) and help obtaining notes from lessons missed (Underdown, 2002). It was

suggested that primary carers “deserve special consideration” because of the levels of responsibilities they are undertaking (Fives et al., 2013, p. 55). The extension or introduction of initiatives based on flexible schooling practices is recommended; some studies assert that “[s]chools need to be flexible in order to meet the needs of young carers” (McAndrew et al., 2012, p.17; Smyth et al., 2011). Warren (2007) advocates specialist support within schools to encourage young carers to “reach their full educational potential” with “[p]ersonalised packages of learning” for individual young carers based on their “needs, aspirations and talents” (p.144). Young carers have identified “perceived significant personal benefits” from their caring role in terms of maturity and experience which “the formal education system does not acknowledge” (Heyman and Heyman, 2013, p.576). It has been recommended that instead of focusing purely on the negative impact of caring, “personal gains from their role need to be better acknowledged” (Heyman and Heyman, 2013, p.577).

It is recommended that a member of staff be identified in every school as a contact for young carers to go to for advice, counselling, to be listened to in a safe environment by someone who understands and who knows how to address any arising concerns (McAndrew et al., 2012; Warren, 2007; Underdown, 2002). Raising awareness about young carers amongst the wider school community to include pupils and encourage greater inclusion is a practical way suggested to address the stigmas associated with being a young carer (McAndrew et al., 2012). This could happen through school assemblies and by including information on young carers in Personal Social and Health Education classes (GB), Learning for Life and Work Classes (NI) and their equivalent (where applicable) worldwide (McAndrew et al., 2012; Underdown, 2002). It has also been proposed that school promotion of mental well-being from an early age, with an element of this being “accepting young people for who they are, which might include having responsibility for other family members”, would both help reduce the stigma experienced by young carers and help their emotional well-being (McAndrew et al., 2002, p.17). School nurses and teachers are described as “pivotal to this process and to ensure the ‘emotional’ well-being of young people” (Ibid).

Using young carers’ organisations based outside of the school/education environment is another practical way recommended for helping young carers in

their place of education. Such organisations taking programmes into schools to raise awareness of, and providing support to, identified young carers “was viewed as a win-win for frontline staff and young carers alike” (Stamatopoulos, 2015, p.12). Stamatopoulos (2015) also outlined the problems of implementing such programmes where “administrative pull-back” and “parental consent restricted their success” (p.13). Problems accessing schools has been highlighted by Thomas et al., 2003. As a recommendation, utilising young carers’ organisations to help schools better identify and support young carers can only work if schools and education authorities are committed to engaging fully with and supporting the programme being offered.

There is a need for young carer specific policies for those participating in education and those who are not because of their caring role (Bjorgvinsdottir and Halldorsdottir, 2014; Hill et al., 2011). Bjorgvinsdottir and Halldorsdottir (2014) suggested that the reason many young carers involved in their study experienced a “lack of emotional and educational support”, was “the lack of well-structured policies for teachers and school nurses to address and support children and adolescents who care for their parents at home”(p.45). Being a young carer has been cited as a reason why a young person may not be in education, employment and training (Hill et al., 2011). To combat this, Hill et al., (2011) suggest the need for “specific and locationally targeted policies and support for education” to help young carers re-enter education, employment or training that takes into consideration their caring roles (p.194). Alongside such policies, Hill et al., (2011) emphasised the need to look further and go as far as identifying “the ways in which services and local infrastructure can support young carers to balance their multiple responsibilities... irrespective of where they live” (p.194). Both these examples highlight a need for young carer specific policies for those in education and for those who would like to be.

Complementing young carers specific policies, Hamilton and Adamson (2013) highlighted the need for “intensive and ongoing formal support services” to limit the impact of the caring role on a young persons’ life (p.115). Heyman and Heyman (2013) describe what these services could entail, they “need to be complemented by helping indirectly through improving services for the relatives they are looking after, promoting family support and increasing the sensitivity of

the educational system (p.577). Pakenham and Bursnall (2006) emphasised the importance of putting such supports in place when they wrote;

With respect to social support, higher levels of qualitative social support were related to higher positive outcomes, less distress and better health, whereas greater number of support people was related to greater life satisfaction (p.716).

3.2.5.1 Recommendations for future empirical research

Further research was suggested by five studies (Kavanaugh, 2014; Hamilton and Adamson, 2013; Cluver et al, 2012; Lackey and Gates, 2001; Gates and Lackey, 1998). The variety of topics recommended for future research illustrates the complexity of this area of study.

Kavanaugh (2014) suggested a need for research focusing on how school can help support young carers of relatives with specific conditions (p.686).

Responses to a questionnaire in Australia “suggested that younger and young adult females were more likely to report greater dissatisfaction with key life areas such as health, education and employment” (Hamilton and Adamson, 2013, p.112). Hamilton and Adamson (2013), write that this finding highlighted the need for further research to examine how gender and the importance of gender, age and duration of care provision may shape “young carers’ frames for action, particularly as they negotiate major lifecourse stage transitions” (p.112).

Cluver et al., (2012) examined the educational impacts on young people caring for AIDS related sickness and other sickness in a household. As a result of their findings they suggested “[i]t is essential that future research determines risk and protective factors for access to education, in order to inform policy and interventions” (p.602).

Lackey and Gates (2001) presented two questions to be addressed in future research and policy. The first question was “when does caregiving really begin and family obligations and duty come into play?” (p.327) The second question

had “where is the line between normal expectations of family life and inclusion of youngsters in caregiving?” (Ibid) This second question has the supplementary question of “how much is too much?” (Ibid). Alongside these two questions, three other recommendations were made for future study. The authors suggested comparing the results from the group of former young carers involved in the 2001 study with other adults to “compare their caregiving experiences” (Ibid). In relation to the types of participants being used, they suggested future research “should include adults of different ethnic, racial or regional groups, and adults who care for parents or grandparents with mental illnesses or other chronic physical illnesses such as AIDs and Alzheimer’s disease” (Ibid). A longitudinal study focusing on “youngsters” and exploring the impact of having a caring role on them over a period of time was also recommended (Ibid).

Due to the small sample size involved in their study, Gates and Lackey (1998) recommended that more general research was required to report, to as full an extent as possible, the tasks being undertaken by young carers and the impact of such caring tasks on them.

3.2.6 Conclusion

A systematic literature search identified 50 relevant peer reviewed empirical studies; nineteen were studies carried out in GB. Out of these nineteen studies, two had a specific link to Northern Ireland (Manderson and McCune, 2004; Roche and Tucker, 2003) but contained no specific information on young carers and education⁶⁶. This highlights the lack of research on the experiences of young carers in education aged sixteen to twenty-four years old in Northern Ireland and emphasises the need for a study focusing on this specific area.

⁶⁶ Further examination showed in the case of Manderson and McCune (2004) due to the nature of the article (a document review of case notes for female patients with children aged 0 to 17), although one area concerned the “educational/cognitive development” of the children involved and two young people raised an enquiry into this, no explanation was given as to what this enquiry consisted of and what the results of these were (if applicable). Roche and Tucker examined the similarities between the experiences of young carers and young people with ME, interviews were noted as taking place “throughout England and Northern Ireland” however results were not reported on a whole and no comment was made about findings in Northern Ireland (Roche and Tucker, 2003).

The literature identified, in general, a strong positive and negative divide in relation to young carers' experiences of school and the impact their caring role had on their education. For those young carers experiencing such an impact on their education by their caring role, these were well documented by the literature and could be categorised under the following headings; lack of recognition, support and understanding, issues surrounding having an adult role at home and being a child in school, confidentiality and intrusiveness, the priority of their caring role, concentration and tiredness, homework and extracurricular activities, absence and lateness, dropping out of school, young carers and their future, poverty and hunger, bullying, stigma and isolation. These problems were presented as occurring in interconnected ways (with young people with a caring role experiencing several together) and to varying degrees of impact upon the young carer.

The inconsistent levels of support and understanding being experienced by young carers in their place of education and the recommendations being made by the research on this same issue shows the importance of examining what support young people with a caring role are given and seeing how this corresponds with academic achievement.

3.3 Non-peer reviewed literature

3.3.1 Introduction

This section seeks to provide a thematic narrative of the non-peer reviewed literature retrieved following a systematic search and follow up searches for grey material. Non-peer-reviewed literature is important for this subject area as a significant amount of literature on young carers takes the form of reports. An outline of the recommendations this material makes for policy and practice will also be compiled and presented.

The positive aspects of young carers and education were outlined in a minority of the literature (Sempik and Becker, 2014a; Family Action, 2012; Szafron and Duerksen, 2012; Tuffrey, 2012; Robotham et al., 2010; Cass et al., 2009; Children's Commissioner for Wales, 2009; Evans and Becker, 2009; Roberts et al, 2008, Newman, 2002; Howard, 2001; Rowntree, 2001; Dearden and Becker, 2000). It was prevalent that a young carers education was negatively impacted through experiences or issues stemming from their caring role (Bignall, 2015; Jarkestig et al, 2015; Bleakney, 2014; Scottish Youth Parliament, 2014; Sempik and Becker, 2014a; Sempik and Becker, 2014b; Bray, 2013; Family Action, 2012; Szafron and Duerksen, 2012; Waugh, 2012; Waugh, 2012a; Mechling, 2011; Hamilton and Adamson, 2010; Robotham et al., 2010; Aylward, 2009; Cass et al., 2009; Children's Commissioner for Wales, 2009; Evans and Becker, 2009; Finnerty and O'Connell, 2009; Hill and Thomson, 2009; Roberts et al, 2008; Moore and Morrow, 2007; Taylor, 2007; Barnardo's, 2006; Morgan, 2006; Kendall et al., 2005; Moore, 2005; Warren, 2005; Becker and Dearden, 2004; Dearden and Becker, 2002; Dearden and Becker, 2002; Howard, 2001; Rowntree, 2000; Frank et al., 1999; Watson, 1999; Aldridge and Becker, 1993; Page, 1988).

After outlining young carers attitudes to education and the differing levels of impact relating to the age of the young carer and the condition of the person they were providing care to, the positive aspects of a caring role and a young person's education will then be focused on. The negative impacts and the recommendations being made for policy and practice will then be discussed

3.3.2 Young carers and education

3.3.2.1 Young carers attitudes to education

Cass et al., (2009) and Evans and Becker (2009) acknowledged the importance that young carers placed on their education.

Evans and Becker (2009) reported that the majority saw “doing well at school and continuing their education” as their main priority (p.182). Education was seen by these young people and their families as “key to improving their employment prospects and life chances” (Ibid). Reinforcing this, Cass et al., (2009) stated that young carers service providers believed that education was both “a highly important matter” for and something that “young carers themselves gave...high priority” to (p.96).

3.3.2.2 Differences in impact between young carers and young adult carers

Differences have been reported about the needs of young carers depending on their age regarding how they felt about the impact of their caring role and the actual impact on their education (Hamilton and Adamson, 2010; Cass et al., 2009; Revans, 2007).

Hamilton and Adamson (2010) interviewed twenty-three young carers aged seven to seventeen and thirteen young adult carers aged eighteen to twenty-five. They found that young carers “generally expressed less concern over the effects of caring on their education and greater satisfaction with their ability to attend school” than the young adult carers (Hamilton and Adamson, 2010, p.4). Young adult carers in contrast “expressed frustration with balancing their education and caring tasks”, be this because of increased levels of caring, increased education workload, course timetables and transport to and from their place of education (Ibid).

A difference between impacts on young carers and young adult carers was also outlined by Cass et al., (2009) who found that “potential young carers” under nineteen years of age “were more likely to still be at school than other young people” (p.57). However, for those aged nineteen to twenty-four years old who were providing care, it was recorded that “they appeared to have achieved lower levels of education” (Ibid).

The needs of young carers in GB aged sixteen to seventeen have been described as different to younger carers based on the Carers (Equal Opportunities) Act 2004 and as such they need their training, employment and leisure needs individually assessed (Revans, 2007).

3.3.2.3 Differences between impact and conditions

Young people providing care for someone with a certain type of condition have been identified as particularly at risk of experiencing problems with their education (Becker and Dearden, 2004). Those caring for someone misusing drugs or alcohol have been described as “especially vulnerable to the risk of missing school and experiencing educational difficulties”, with four out of ten young people in this situation having “educational difficulties” (Becker and Dearden, 2004, p.14, p.17). It has also been commented that for young carers of parents with a mental illness “which is unpredictable and prevents forward planning”, the impact of their caring role is “exacerbated” by having to provide high levels of emotional support (Roberts et al, 2008, p.6).

In addition, a link has also been suggested between young carers experiencing bullying and stigma and the condition of the person they are providing care for (Robotham et al., 2010; Morgan, 2006). Robotham et al., (2010), described young carers as “often” reporting bullying which “may have been linked with the stigma associated with mental illness” (Robotham et al., 2010, p.19). Similarly, Morgan (2006) commented on young carers being bullied at school and this bullying including comments being made about their parents with a disability.

3.3.3 Positive aspects of young carers and education

It has been said that a young person with a caring role can develop beneficial “real world skills” (Tuffrey, 2012; Robotham et al., 2010; Roberts et al., 2008, p.6; Newman, 2002; Howard, 2001; Rowntree, 2001). Participants in the research of Rowntree (2001) reported that the skills they had gained through their caring experience, were generally “more relevant” than formal learning (p.1). In caring situations when a young carer “is well supported”, Roberts et al (2008) stated that such skills could “facilitate the transition to adulthood and lead to very positive outcomes for young carers” (Roberts et al., 2008, p.6). These skills are documented as consisting of; higher levels of maturity (Roberts et al., 2008; Newman, 2002), better coping abilities (Roberts et al., 2008), increased competencies (Newman, 2002), “a sense of self-efficacy” (Robotham et al., 2010, p.18) and increased understanding and compassion “of those with disabilities” (Tuffrey, 2012, p.93).

Some young carers presented the positive view of school as an “escape” (Szafron and Duerksen, 2012, p.14). Not all were reporting that their education was negatively impacted because of their caring role (Scottish Youth Parliament, 2014; Sempik and Becker, 2014a; Family Action, 2012; Evans and Becker, 2009). For example, 44.0% of participants were reported by Family Action (2012) as saying they experienced no difference with their schoolwork because of caring (p.25). Likewise, 26.2% of participants responded that their caring role did not affect their schoolwork and 34.4% of focus group participants did not believe it was more difficult for them to do well at school because of their caring responsibilities (Scottish Youth Parliament, 2014, p.16). Evans and Becker’s (2009) research in GB and Tanzania also reported that over a third of young carers did not think their caring role impacted on academic performance or attendance (p.181).

Despite caring responsibilities, young carers are ambitious and not deterred from planning to and engaging in further education (Cass et al., 2009; Children’s Commissioner for Wales, 2009; Dearden and Becker, 2000; Evans and Becker, 2009). They have “high aspirations” and optimism about their futures, they want to continue their education and gain employment (Cass et al., 2009, p.84;

Children's Commissioner for Wales, 2009; Evans and Becker, 2009). In Welsh research, 53.0% of young carers said they wanted to go to college or university or get a job after school and 62.0% of participants indicated they thought they would go on to university (Children's Commissioner for Wales, 2009, p.51).

Despite experiencing problems with their caring role, young carers are engaging in further education (Dearden and Becker, 2000). Sempik and Becker (2014a) even reported 79.0% of research participants said they were doing well at university and college and enjoying themselves in spite of difficulties associated with their caring role.

In situations where young carers succeeded in education this was credited to the individual young carer, their own "high aspirations...interest and motivation" and support from their parents, friends and "individual teachers" and not due to "supportive institutional environments or sensitivity and awareness of young caregiving among school professionals" (Evans and Becker, 2009, p.199). Frank et al., (1999) wrote that in situations where young carers did well at school, their success "often depended on the ability of the young carer to organise their day, cope with family pressures and crises, and where necessary, limit social activities or work extraordinary long hours" (p.16).

This emphasises the need to address areas such as teacher training and the formulation and implementation of policy and procedures within places of education to help support young carers. Tertiary education has been identified as being more accommodating to young people with a caring role (Hamilton and Adamson, 2010). Research into the reasons why and how this is the case could potentially inform how secondary level education can adapt to help support young carers in school (Hamilton and Adamson, 2010).

3.3.4 Negative aspects of young carers and education

Navigating one's way through education can be a difficult task for any young person. Add to it significant care responsibilities...; poverty; isolation; physical, mental and emotional strain; ignorance; system inflexibility and irrelevance and the task becomes almost impossible (Moore, 2005, p.55).

What follows is a discussion of how a young person's education has been documented as negatively impacted upon because of their caring responsibilities. These factors have been described as combining to increase the risk of restricting a young carer accessing "satisfactory outcomes in education and place them at-risk for early school leaving" (Moore, 2005, p.52-53).

3.3.4.1 Prevalence of young carers reporting education was impacted negatively by their caring role

Seven studies presented statistics that showed the prevalence of young carers' educations being impacted negatively by their caring role ranging from 20% to 70% of young carer samples recruited (Sempik and Becker, 2014a; Bleakney, 2014; Children's Commissioner, 2009; Evans and Becker, 2009; Barnardo's, 2006; Frank et al., 1999).

- Sempik and Becker (2014a) reported that of the 79.0% of young adult carer respondents at college or university who said they were doing well with their education, 56.0% of these same young adult carers said they "were experiencing difficulties because of their caring role".
- One in five young carers enrolled in school interviewed by Bleakney (2014) described their studies as "affected as a result of their caregiving responsibilities" (p.6). This was reported by 37.0% of young carers providing a minimum of ten hours care a week compared to 14.0% of young carers caring less than ten hours a week (Ibid).

- Almost half (49.0%) of participants in research by Family Action (2012) said their education “had been affected by issues relating to being a young carer” (p.25).
- A study by The Children’s Commissioner for Wales stated that 63.0% of respondents revealed that they sometimes to always fell behind with their school work because of their caring role.
- Evans and Becker’s’ (2009) research recorded that two thirds of young carer respondents in Tanzania thought caring had a negative effect on academic performance, noting that a higher proportion of females reported this as the case.
- In a Barnardo’s Report, 43.0% of young carers said their school was affected by caring role (Barnardo’s, 2006).
- Just under three quarters (70.0%) of those surveyed by Frank et al., (1999) “specifically stated that their education had been affected by their caring responsibilities” (p.16).

Two of these studies also presented statistics relating to young carers doing well at school (Sempik and Becker, 2014a; Evans and Becker, 2009).

3.3.4.2 Identification of young carers

Research involving education staff and school counsellors highlighted that young carers were hesitant to come forward and often do not want to be identified because of fear (Szafron and Duerksen, 2012; Robotham et al., 2010). School counsellors recognised that young carers wanted to keep their home life private, that there was a sense of fear “that someone will learn about their chaotic home life” (Szafron and Duerksen, 2012, p.11). Other education professionals linked

young people not wanting to be recognized for “fear of stigma and discrimination, or concern about parental criticism” (Robotham et al., 2010, p.19). Research from Tanzania, illustrates this point, here almost half of young carers researched said their teachers knew of their caring role but not about their parents illness because they feared being stigmatised (Evans and Becker, 2009).

Teachers missing or misreading the signals indicating a problem with a young person’s home life was cited as a reason why young carers are not being identified as such within their place of education (Watson, 1999). For example, instead of interpreting “unexplained lateness, truancy and parents’ non-attendance at parents meetings” as a sign of difficulties in the young person’s home situation it is instead “missed or misconstrued as bad behaviour” (Watson, 1999, p.40). This evidences the need to increase awareness and to train teachers and other education professionals to identify and support young carers.

Another explanation was offered by Szafron and Duerksen (2012) as to why teachers may not be aware of children’s family situations in their classrooms. This was that teachers simply do not have the opportunity “to discuss home life” with the children they are responsible for teaching due to “the nature of classroom organization” (Szafron and Duerksen, 2012, p.11).

3.3.4.3 Lack of understanding and support

Young Carers were documented as experiencing varying levels of understanding and support in their place of education. A study carried out by the Children’s Commissioner for Wales illustrated 54.0% of participants said that the support they had received was “OK or better than OK”, but 54.0% also said they felt they only received support when there was a crisis and 36.0% said the support they received from their school was “poor or awful” (Children’s Commissioner, 2009, p.31, p.35). Young carers experiencing a dramatic lack of understanding and support in school was shown in Family Action (2012) and Barnardo’s (2006). Under half (42.0%) of research participants in Barnardo’s (2006) said that they had been “punished” by teachers when their work had been impacted “as a direct result of their young carer responsibilities” (Barnardo’s, 2006, p.8). Young carers

being punished in school for issues relating to their caring role was also reported by some young carers (not quantified) in the Family Action (2012) Study. This report also highlighted that little support was shown by schools even when aware of a young carer's situation (Family Action, 2012).

Robotham et al., (2010) who researched young people with parents with severe mental illness recorded that most young carers had "low expectations" of how school would and could help them, with often situations for a young carer reaching crisis point before school took notice (Robotham et al., 2010, p.19). Cass et al. (2009) wrote that many of the young carers participating in their research reported that teachers were aware of their situation and helped them however others were "disappointed" by the lack of help they received, also others said that even though teachers knew about their situation "they felt that their teachers' priorities and their own priorities were at odds" (Cass et al., 2009, p.75). Mixed opinions on school counsellors was also touched upon in this research, being described as either annoying or supportive, with young carers reporting that they just wanted school counsellors to listen to them.

Finnerty and O'Connell (2009) in their Irish study concluded that most young carers "received little or no support from their schools and there was little intervention to ensure that their education was not affected" (p.20). Similarly, former young carers had the perception that school was not a supportive environment for them and emphasised that 'the load of school and home demands ultimately took a huge toll' (Szafron and Duerksen, 2012, p.14). The work of Hamilton and Adamson (2010) and Moore and Morrow (2007) also showed young carers experiencing a lack of awareness and understanding. Hamilton and Adamson (2010) commented specifically on a lack of understanding highlighting a difference between individual teachers and "school-wide" (p.4).

An example given by a young carer of a teacher acting in a way that was felt inappropriate when their caring role was identified, shows how teachers can be in the awkward situation of wanting to support a young person but not acting in a way that the young person felt was appropriate because they do not know what else to do (Watson, 1999). In this instance, the young carer's teacher offered to help them at home and asked their classmates to donate towards buying the

young carers ill parent a present (Watson, 1999). This illustrated advice given by Morgan (2006) that for young carers there is a “fine line between helping and intruding” (p.18). This both emphasises and further evidences the need for increased awareness about young carers amongst teachers and training to support teachers when they are faced with these situations.

3.3.4.4 Problems balancing the caring role

Half of young carers reported by Evans and Becker (2009) in GB and Tanzania said caring “conflicted” with their “private study and school work time” (p.179). In Tanzania “some” young people “found it difficult to negotiate time and space for themselves to study within a context of poverty and overcrowded living conditions” for example using a kerosene lamp when sick relative wanted to sleep (Ibid). In other research, participants in focus groups reported not just “strains with respect to their efforts to combine school education and care” (p.x) but also when it came to them entering further education and training, showing that such a “juggling act” can continue after school into further education and training (Cass et al., 2009, p.78).

A potential consequence of balancing a caring role with education was suggested by Morgan (2006), who identified reduced/poorer educational outcomes impacted on their “chances of getting a good job later in life less than they would have been” (p.19).

Based on the work of Hamilton and Adamson (2010) it has been suggested that for most young carers and young adult carers, despite the balancing act that they have to perform, their caring role was “their priority” (p.4).

3.3.4.5 Concentration and behavioural problems

Young carers experiencing problems with concentration or feeling distracted in class was mentioned by Bleakney (2014); Scottish Youth Parliament (2014); Family Action (2012); Cass et al., (2009); Page (1988). In a report from the Scottish Youth Parliament, just over half (50.8%) of participants said that they were distracted in class because of their caring role (Scottish Youth Parliament, 2014).

The negative impact of a young person's caring role on their behaviour at school was touched upon by Family Action (2012), Morgan (2006) and Frank et al., (1999). Family Action (2012) recorded that "[m]any young carers recognised that their behaviour in school could sometimes be disruptive and poor" (p.28). The reasons suggested for this behaviour were frustration at not being understood and/or feeling that they were not being supported.

3.3.4.6 Worry and stress

The emotional impact of a young person providing a caring role is described in terms of stress, worry and anxiety. (Family Action, 2012; Children's Commissioner, 2009; Evans and Becker, 2009; Page, 1988).

Evans and Becker (2009) and Page (1988) refer to young carers experiencing worry, stress and anxiety but do not give any context/explanation as to how or why this is the case. Research from the Children's Commissioner for Wales (2009) offered more statistical detail. Over half (64.0%) of respondents said they felt stressed about school/college with 44.0% feeling really stressed. When asked about what they worried about most, 26.0% said 'family problems', followed by 24.0% saying 'school/work' (p.38). Family Action (2012) explained that young carers are unable to "leave home behind" and forget about the person they care for while they are at school which could account for their worries about their family (p.29).

When asked how stress could be reduced for young carers, raising awareness about young carers and increasing staff understanding in schools was suggested as a solution (Children's Commissioner, 2009, p.14).

3.3.4.7 Tiredness

Tiredness has been identified as impacting on a young carer's education (Scottish Youth Parliament, 2014; Family Action, 2012; Cass et al., 2009; Evans and Becker, 2009; Frank et al., 1999). The only statistic found in relation to young people experiencing tiredness because of their caring role was presented by Scottish Youth Parliament (2014), where 49.2% of participants agreed that "Yes, I am sometimes tired in school" (p.16). In an extreme example of tiredness impacting on a young carer's education, Cass et al., (2009) commented that young carers reported that they had fallen asleep at school because they were up late with homework after their chores.

3.3.4.8 Problems with peers and social isolation

Young carers were described as feeling different at school and as having trouble fitting in with their peers (Cass et al., 2009; Morgan, 2006). Cass et al., (2009) recounted:

Many felt that their caring experiences set them apart and made them different from their peers. This feeling of 'being different' coupled with the 'highs and lows' of being an adolescent meant a number of young adult participants in this research reflected on their high school years as a period of emotional turmoil (p.77).

Some young carers were noted saying, "that their classmates would often feel disgruntled by what they perceive as 'special treatment'" should the young carer be given support in the form of flexibility from a teacher (p.76).

Young carers feeling isolated or being isolated was outlined by Finnerty and O'Connell (2009), Moore and Morrow (2007) and Frank et al., (1999). Former young carers recalled school as being a "painful social experience" involving feelings of "isolation, frustration and depression" (Frank et al., 1999, p.16). Young carers absenteeism from school also meant they missed out on the opportunity to develop everyday relationships with their peers (Finnerty and O'Connell, 2009). They also have "[n]o time for extracurricular activities", reducing their opportunities to engage with their peers and embarrassment leads them to not disclose their caring role to their friend's due to fear of how they will react and the consequence of it (Waugh, 2012).

3.3.4.9 Bullying and stigma

Szafron and Duerksen (2012) research of former young carers reported that "[o]ne disturbing overriding theme was bullying" (p.14). Young carers experiencing bullying at school was also referenced in the literature by Scottish Youth Parliament (2014), Waugh (2012a), Robotham et al. (2010), Aylward (2009), Evans and Becker (2009) and Morgan (2006).

Some young carers explained that they were bullied at school because their peers did not understand their caring responsibilities or because they were "unable to afford certain items and outings" (Scottish Youth Parliament, 2014, p.32). Other young carers reported bullying "which may have been linked with the stigma associated with mental illness or being a young carer" (Robotham et al., 2010, p.19). Morgan (2006) wrote that bullying was "exacerbated" in some situations by young carers having to explain to their teachers in front of their class about the non-completion of schoolwork (p.9).

3.3.4.10 Absence and lateness

Young people missing school because of their caring role was highlighted by Bleakney (2014); the Scottish Youth Parliament (2014), Sempik and Becker (2014a), The Children's Commissioner for Wales (2009), Cass et al., (2009), Evans and Becker (2009), Finnerty and O'Connell (2009), Becker and Dearden (2004), Dearden and Becker (2000) and Rowntree (2000) Frank et al., (1999) and Page (1988).

Becker and Dearden (2004) reported that the rate of young carers missing school dropped in their samples from 1995 to 2003. This was accredited to awareness raising in schools about the difficulties young carers face educationally and young carers project staff working within schools to increase awareness and work with teachers. No other longitudinal study has been completed since then to provide a more up to date comparison.

Young carers missing school and having a lack of, or no GCSE's is presented side-by-side in the work of Dearden and Becker (2000) and Rowntree (2000). Rowntree (2000), interviewed young people aged sixteen to twenty-five years old who were currently caring for or who had cared for a parent and described a "large proportion" of respondents saying that they had "educational problems and missed school" (p.1). Half of participants "had missed school and a quarter had no GCSE's", the "majority" said that they had missed school due to a caring role (p.2). Likewise, Dearden and Becker (2000) interviewed sixty children and young people between the ages of sixteen and twenty-five and focused on how their caring role had influenced their transition into adulthood. A quarter of this sample had no GCSE's and half of participants reported they had missed school with most of those missing school giving their caring role as the reason why.

The research of Sempik and Becker (2014a), Children's Commissioner (2009) and Evans and Becker (2009) gave further statistics about the frequency young carers were missing school and how many young carers were in this situation. Participants on average in a study by Sempik and Becker (2014a) "had missed one and a half days in the previous two weeks because of their caring role" (p.15). Just over a third (34.0%) of participants in Children's Commissioner for

Wales research (2009) recorded sometime to always missing a day off school because of caring. Evans and Becker's (2009) research in GB and Tanzania found most young people reported missing school with more girls in Tanzania doing so than boys.

A financial implication of missing school was outlined by a Scottish Youth Parliament (2014) report and Taylor (2007). The Scottish Youth Parliament (2014) report stated out of the 19.0% of young carers researched receiving Educational Maintenance Allowance (EMA) payments, 45.5% said they had lost a payment due to absences linked to their caring role. This is despite the fact that guidance issued to schools "specifically calls on them to take into account whether a pupil may be a carer before penalising them for missing lessons" (Taylor, 2007, p.18-19).

Some young carers admitted to taking time off to manage the demands of their caring role (Cass et al., 2009). It was also reported that in some instances teachers and education welfare staff had "colluded" in young carers absences, with Dearden and Becker (2000) suggesting that these professionals had the "mistaken belief that this was a supportive course of action" (p.9).

Young carers have been affected by truancy policies that do not take into consideration the needs of those young people providing care (Taylor, 2007). A representative of The Princess Royal Trust for Carers expressed the view that such policies focus on "truancy sweeps, when young carers will be at home and on prosecuting parents" (Taylor, 2007, p.18). They argued that parents cannot be prosecuted for their child's absence from school "when the reason they are off in the first place is to help meet their parent's community care needs" (Ibid). The research of Family Action (2012) highlighted one family who had been fined because of "persistent absence" (p.25). The authors of this report wrote that because of the amount of pressure being placed on schools to improve attendance "it is not a surprise that teachers place a lot of pressure on young carers to be in school" (p.26). Interestingly, one of the families involved in this research described absence as a "a way to get the school interested in the caring role the young person played" as it was "likely to provoke a response" (p.27).

In addition to missing school, young carers have been documented as being late to classes because of their caring role (Scottish Youth Parliament, 2014; Sempik

and Becker, 2014a; Family Action, 2012; Waugh, 2012; Evans and Becker, 2009; Page, 1988). The numbers of young carers reporting their education impacted in this way varied throughout the literature, for example, 24.6% of participants reported they were sometimes late to class in research carried out by the Scottish Youth Parliament (2014) compared to 60.0% of participants saying they had “problems with punctuality” in research carried out by Family Action (2012). Sempik and Becker (2014a) reported in a general way that on average participants had in the previous two weeks been late at least once because of their caring role. A Tanzanian study described how young carers suffered as a result of being late to school, with Evans and Becker (2009) stating that being late to school “sometimes resulted in corporal punishment and having to miss further classes” (p.77).

3.3.4.11 Less time to study and problems with schoolwork

Young carers having less time to study than their contemporaries were outlined in the work of Bleakney (2014), Scottish Youth Parliament (2014) and Waugh (2012). Only the Scottish Youth Parliament (2014) reported a statistic on this impact, 34.4% of participants said they had less time to study (Scottish Youth Parliament, 2014).

Young carers having difficulties completing homework's, coursework or assignments were mentioned by (Scottish Youth Parliament, 2014; Family Action, 2012; Waugh, 2012; Cass et al., 2009; Morgan, 2006; Page, 1988). No statistics were given.

3.3.4.12 Exams

Young carers have been reported as experiencing problems in relation to exams because due to their caring role impacting on their ability to attend exams and exam preparation (Evans and Becker, 2009; Kendall et al., 2005).

In the GB section of their study, Evans and Becker (2009) stated that “in a few instances” young carers had missed exams because of their caring role (Evans and Becker, 2009). No further statistics were offered.

Kendall et al., (2005) focused on the barriers to vulnerable children accessing exams, including gaps in education, missing preparation classes as well as them finding it difficult to concentrate during exams, missing exams, and being late to exams. They emphasised that young carers are not automatically eligible for special consideration when sitting exams, highlighting the importance of proactively identifying young carers in case they should need to apply for special consideration when sitting exams.

3.3.4.13 Low grades

Young carers low academic achievements were identified in the research of Sempik and Becker (2014b), Aylward (2009), Roberts et al (2008), Warren (2005), Rowntree (2000) and Dearden and Becker (2000), with a gap between the educational attainment, participation in school and in a workforce of young carers and young non-carers identified by Bray (2013).

It was argued that young carers are “at risk of lower educational attainment because of interrupted school attendance, reduced performance, or inability to participate in school activities alongside their peers” (Roberts et al, 2008, p.6).

Sempik and Becker (2014b), surveyed seventy-seven young adult carers who had left school and were NEET or providing high levels of care. The highest held qualification by respondents were GCSEs at the grades D-G (28.0%), 49.0% had GCSEs, 12.0% had university degrees and 8.0% of those no longer in education had no qualifications. Earlier research by Dearden and Becker (2000) recorded that out of the sixty children and young people they interviewed between the ages of sixteen and twenty, a quarter of the sample had no GCSE's.

Bray (2013), when comparing 2006 census data on young carers with data from Australia's Department of Families, Housing, Community Services and Indigenous Affairs, identified a “very large gap” between young carers and other

young Australians and their levels of educational attainment (p.37). The educational attainment of young carers, their participation in school and in a workforce, were described as “generally low” (p. viii).

A belief was highlighted among some young carers that it was harder for them to do well and that they felt they would have “got better grades” had it not been for their caring role (Sempik and Becker, 2014b, p.3.). For example, 52.5% of research participants believed it was harder for YCs to do well (Scottish Youth Parliament, 2014). In another study, 54.0% of young carers felt would have got higher grades had it not been for their caring role (Sempik and Becker, 2014b).

The impact of low grades upon a young carer’s future will be discussed in the section 3.3.5 ‘Transition: young carers and their future’

3.3.4.14 Dropping Out

Young people having to drop out of their education or concerned they may have to drop out of their education because of their caring role or for financial reasons was referenced in the work of Sempik and Becker (2014a), Sempik and Becker (2014b), Scottish Youth Parliament (2014), Cass et al., (2009) and Finnerty and O’Connell (2009).

Cass et al., (2009) described a “number of young adult carers” as disclosing how the pressures they experienced in their caring role “led them to drop out of high school” (p.77). Sempik and Becker (2014b) reported that eleven out of the thirty-eight participants involved in their study who had been to university/college had dropped out because of their caring role, with the drop out rate for young carers at university being “four times greater than the national average for degree courses” (p.3). In another report by Sempik and Becker (2014a), 14.0% of participants were “concerned that they might have to drop out of college or university” because of their caring responsibilities (p.3). Other research identified “many respondents” considered leaving education due to financial problems (Scottish Youth Parliament, 2014, p.32). An example was given in another study

of a young carer having to leave education and take on employment because of poverty in the family (Finnerty and O'Connell, 2009).

3.3.4.15 Financial hardship and poverty

Financial hardship was reported as experienced by young carers who continued into further education by Sempik and Becker (2014b), Scottish Youth Parliament (2014), Dearden and Becker (2000) and Rowntree (2000). Rowntree (2000) highlighted that despite young carers experiencing problems at school, “many had continued into further education” but in doing so they experienced financial hardship (p.3). Likewise, Scottish Youth Parliament (2014) stated that “a majority” of their respondents believed their financial situations limited the opportunities open to them and made them contemplate leaving education (p.32). For example, 85.7% of participants said finances affected their “ability to attend classes” and 73.2% of participants said it limited their opportunities to participate in extra lectures or internships (p.18). Caring responsibilities made it difficult for these young carers to work part time while studying which further helped to compound their financial problems and limit their options (Rowntree, 2000).

Poverty in the family was given as the reason one young carer had left school to take on employment (Finnerty and O'Connell, 2009). This concept of poverty in young carers families was presented in data from Bray (2013) and Warren (2005) showing young carers were more likely to live in families that are ‘financially worse off’ (Warren, 2005, p.8). Analysis of the dataset from the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) of those aged under twenty-five years old receiving Carer Allowance or Carer Payment or both, reported young carers being “nine times more likely to be living in areas of high socioeconomic disadvantage” (Bray, 2013, p.viii).

Supporting this, the work of Evans and Becker (2009), in the GB element of their study found that “some children and parents also highlighted issues related to poverty as impacting on children’s education” (p.186). Many of these families were described as living on low incomes in social housing with limited space available for studying (Ibid). “Several” of these families did not have a computer

or access to the internet at home which caused problems for young carers wanting to complete coursework (Ibid). It has been commented that young carers “are more common in single-parent families...and families with unemployed parents or on low incomes (SCIE, 2005, pp.3-4). Evans and Becker (2009) write that “poverty, particularly in low-income countries is likely to have just as significant an impact on children’s school attendance and performance as children’s caring responsibilities” (p.184). This point was emphasised by the Tanzanian aspect of this study. Half of study participants in Tanzania (young people and parents) raised issues of being unable “to afford exercise books, school uniforms, school meals, secondary school fees, examination fees and other contributions” (Ibid). Not being able to afford such thing led to additional problems for the young person such as “being sent home from school”, corporal punishment and missing school (Ibid).

Poverty impacting on young carers abilities to have the correct uniform, resources and attend school trips was also highlighted in an Australian study and linked to increasing a young carers sense of social isolation (Moore and Morrow, 2007).

3.3.5 Transition: Young carers and their future

The ambition and aspirations of young carers wanting to continue with their education and go from school, to college, university, training or employment, was highlighted by Hamilton and Adamson (2010), Cass et al., (2009, Children’s Commissioner (2009), Evans and Becker (2009) and Rowntree (2000).

A study by the Children’s Commissioner for Wales reported that 53.0% of respondents wanted to go to college or university or get a job after school, with 62.0% saying they thought they would go to on to university. Young carers were reported elsewhere as having “high aspirations” and optimism about their future (Cass et al., 2009, p.84) and as wanting to continue with their education to help facilitate this (Evans and Becker, 2009). This ambition and the choices being made to make such aspirations a reality is however noted as being impacted and influenced upon by their caring responsibilities (Hamilton and Adamson, 2010; Cass et al., 2009; Rowntree, 2000). Hamilton and Adamson (2010) reported that

for young carers and young adult carers, caring did not impact on their ambition to go to university but it often impacted on their decisions “concerning further education” such as their choice of university, the course they choose and the hours involved (p.4). Similarly, it was acknowledged by Rowntree (2000) that for young carers the transition from school to employment was influenced by caring responsibilities and other factors (Rowntree, 2000). Cass et al., (2009) stated that a number of young carers involved in their study “envisaged their caring role would continue and could see that it could place some constraints on their future plans” (p.84). Of these same young carers, Cass et al., (2009) reported they were “conscious that caring had shaped their plans and could identify the benefits of their caring role” (p.84).

Many young carers have been described as having their “occupational aspirations” formed by their caring role (Cass et al., 2009, p.84). Due to low academic attainment, it has been commented that some young carers are restricted to obtaining unskilled, lower paid jobs and those which utilise the skills that they have acquired through their caring role (Bignall, 2015; Roberts et al., 2008).

Finance has a significant impact on young carers and their future (Scottish Youth Parliament, 2014; Sempik and Becker, 2014b; Dearden and Becker, 2000; Rowntree, 2000). Those young carers participating in further and higher education have been described as “more affected by finances than those in school” (Scottish Youth Parliament, 2014, p.18). (See section 3.3.4.15 ‘Financial Hardship and Poverty’.)

Young carers were identified by Warren (2005) as being more likely to identify barriers in their future, one of which being “a lack of qualifications” (p.9). A lack of qualifications or “poor educational qualifications” has been underlined in the literature as a significant problem for those young carers seeking employment (Sempik and Becker, 2014b; Bray, 2013; Aylward, 2009; Warren, 2005; Roberts et al, 2008; Dearden and Becker, 2000, p.9; Rowntree, 2000). Rowntree (2000) and Dearden and Becker (2000) linked “poor educational qualifications” and missing school to young carers being at a “disadvantage” when wishing to access the labour market (p.9). Sempik and Becker (2014b) described their findings on this issue as “controversially” suggesting that; young people with caring role may

not be finding work because of their educational qualifications rather than *choosing not to work* to fulfil their caring roles” (p.13). However, Sempik and Becker (2014b) suggest that the reality was;

...likely to be a combination of lower qualifications coupled with growing expectations for young adult carers to provide ongoing care that lead to a higher proportion of lower qualified young adult carers who are NEET (p.13).

Young carers linked to being NEET was referred to in the work of Bignall (2015); Audit Commission (2010); Aylward (2009) and Hill and Thomson, (2009). The Audit Commission (2010) and Hill and Thomson (2009) presented information showing how being a young carer increased the likelihood of a young person being described as NEET compared to non-carers. In GB, young people aged eighteen and over with caring responsibilities were twice as likely to not be in education, employment or training for six months or more (Audit Commission, 2010) Showing less of a difference, Australian census figures stated that “14% of young female carers aged 15-24 years were not engaged in education or employment....compared with 9% for young men and 11% for young women who were not carers” (Hill and Thomson, 2009, p.12). Hill and Thomson (2009) noted that the regions where young carers were not in education, employment or training tended to be remote which “could reflect high youth unemployment in these regions generally, or that carers are particularly disadvantaged” (p.13).

For those young carers gaining employment it has been documented that some have; missed or been late to work, had to reduce their work hours and/or had to leave their job because of their caring role (Bignall, 2015; Bleakney, 2014).

3.3.6 Recommendations

Recommendations made by the literature to support young carers and young adult carers in their education focused on; involving young carers in formulating methods, policy, and procedure; raising awareness; teacher training; allocating a key member of staff to support young carers; flexibility; understanding; sensitivity; confidentiality; proactively identifying and supporting young carers through policy and practice; practical support; the role of local authorities and governments and examining the methods of intervention in situations when the education of a young carer is affected.

Young carers need to be involved in formulating the methods best suited to support them and in influencing policy and procedure/practice to help them meet their educational needs. It has been argued that “it is perhaps only by seeing these children’s lives through their eyes that we can begin to address the issue of how best to intervene and support them on their terms” (Aldridge, 2008, p.262).

Schools are “key sites for identifying and supporting young carers” (Hill and Thomson, 2009, p.13). Finnerty and O’Connell (2009) promoted the need for “a supportive and aware educational environment” for young carers that extends to distance learning and vocational training (p.24). It is therefore important that places of education promote “a culture where young carer’s can ask for help without fear of bullying or stigma” (Barnardo’s, 2006, p.11). Schools need to provide a safe environment for young carer’s “to go to discuss their problems” (Robotham et al., 2010, p.30). Awareness, therefore, must be raised in schools, particularly with teachers, on the issue’s young carers face (Szafran and Duerksen, 2012). Watson (1999) concluded that it is “only with” an increased awareness about young carers among professionals that such young people will have “the opportunity to enjoy fully their rights both as children and as carers” (p.40).

Training staff about young carers is an integral part of raising awareness about young carers in schools. Teacher training should be targeted/focused upon to identify and raise awareness of the needs of young carers (Family Action, 2012; Hill and Thomson, 2009; Barnardo’s, 2006). Such training could be included in

teaching degree programmes as well as being a part of “in-service training” for teachers already in post (Watson, 1999, p.40).

Schools should identify “a school lead” (Robotham et al., 2010, p.30), a “designated member of staff” (Barnardo’s, 2006, p.11) a “single contact point” (Cass et al., 2009, p.96) for both young carer’s and their families for advice and links to young carers services. Should a member of staff identify a young carer, they could then speak to the school lead on young carer’s and that young person could be efficiently signposted to support services (Robotham et al., 2010). They could also work to develop links between schools and young carers’ organisations (Moore and Morrow, 2007). It has been suggested that information packs should be produced for teachers to help them with the identification of young carers and outline the issues they face (Barnardo’s, 2006; Watson, 1999).

Young carers need to be given flexibility within their place of education. This was the most recurrent recommended method of support outlined in the literature (Waugh, 2012; Robotham et al., 2010; Alyward, 2009; Cass et al., 2009,; Hill and Thomson, 2009; Roberts et al., 2008; Morgan, 2006; Moore, 2005). This flexibility was recommended to be extended to; known young carers and their attendance, homework, coursework and tests (Waugh, 2012; Robotham et al., 2010) and the expectations of young carers and their education (Morgan, 2006). Moore (2005) explained the reason why implementing flexibility towards young carers with their education is important when he writes “[r]igorous and set expectations of students in many schools...preclude many young carer’s from accessing education” (p.54).

Schools and teachers need to exercise understanding towards young carers (Robotham et al., 2010; Cass et al., 2009; Hill and Thomson, 2009). Morgan (2006) gave suggestions of what staff working with young carers should be “taught” to support young people with a caring role and therefore seek to promote understanding (p.18). This included examining areas such as “what young carer’s do”; increasing “awareness of disabilities”; informing staff that young carer’s may be stressed at school which could make them not act like themselves (for example misbehave); knowing that how or if a young person needs support “depends on the needs and wishes of each individual carer”; and that having a

caring role can impact on a young person's ability to interact and "get on" with their peers (Ibid, p.18).

Advice has been given about how teachers should act towards those young people being identified as young carer's, that they need to be treated with sensitivity (Robotham et al., 2010; Aylward, 2009) and confidentiality (Robotham et al., 2010). Further recommendations made for teachers to support young carers in education, show the difficult position they are in when trying to act in an appropriate way towards young carers. Young carers quoted in the work of Morgan (2006) said that "it is important that staff notice when you may need to talk or need help, but that they shouldn't keep asking if you're ok" or intrude (p.17).

Schools need to put in place and promote policies and practices to pro-actively identify and support young carer's (Family Action, 2012). Questionnaires could be utilised for example when young people change schools to make their new place of education aware of "any special support needs that parents consider they or their children might have" (Ibid, p.43). Children who may be "vulnerable" could be proactively identified through the information that schools have about which pupils receive free school dinners (Ibid).

Other practical methods of supporting young carers were recommended by Peel and Beckley (2015), Waugh (2012), Cass et al., (2009), Finnerty and O'Connell (2009), Morgan (2006), and Page (1988). Such methods included; respite care for the person the young carer was caring for so they can be checked on while they were at school (Cass et al., 2009); allowing young people access to a telephone (Cass et al., 2009); tutoring for young carers (Waugh, 2012); breakfast and lunch programmes (Waugh, 2012); use of home schooling, being educated on and off site (Cass et al., 2009; Moore and Morrow, 2007); "recognition for the skills acquired" by young people through caring (Finnerty and O'Connell, 2009; Moore and Morrow, 2007) and having school counsellors to provide "recognition, support and follow up" (Waugh, 2012). To encourage young carers to participate in Further Education, the Australian example was given of universities working on "retention programs" to support such young people during their time at university (Peel and Beckley, 2015, p.377).

Local authorities need to develop and promote strategies "to underpin and encourage activity to support young carer's in and out of school" and where these

authorities commission young carer's services they should be working to improve and encourage partnership working between young carer's services and schools in the same location (Family Action, 2012, p.44).

Governments need to strengthen guidance for places of education to support young carer's and "introduce a duty" via legislation⁶⁷ on schools "to identify and access vulnerable pupils" in their care and provide and "promote adequate support for them" (Family Action, 2012, p.44). Governments also need to also ensure that the relative receiving care from a young carer is "provided with adequate and appropriate care options" (Moore, 2005, p.52), so that young carers can access and participate in education and that "systemic, cultural and practical barriers" to young carers education are addressed by policy-makers (p.55).

There is a need to examine the methods of intervention and young people's perceptions of such interventions in situations where a young carer's education is threatened (Aldridge and Becker, 1993). Young carer's knowledge of traditional methods of intervention could be described as a hindrance to young people coming forward and asking for help (Aldridge and Becker, 1993). Writing in 1993, Aldridge and Becker (1993) suggested that children with caring roles may have

...become willing participants in their own silence, in order to avoid separation from their families" because of the traditional method of intervention by "social services and education welfare officers...to prosecute and to put children into care where the child's welfare, education and development is threatened (p.460).

3.3.7 Conclusion

Non peer-reviewed literature outlining positive aspects of a relationship between young carers and education was in a minority. Only five positive aspects were identified in relation to young carers and education. Firstly, the development of

⁶⁷ Family Action (2012) named specific legislation in the United Kingdom (The Children and Families Bill) when outlining this recommendation, however this was generalised above as it was felt this was more appropriate when outlining recommendations that could be implemented in other countries- not just the United Kingdom.

“real world skills” through their caring role (Tuffrey, 2012; Robotham et al., 2010; Roberts et al., 2008, p.6; Newman, 2002; Howard, 2001; Rowntree, 2001). Skills which some young carers described as “more relevant to growing up than formal learning” (Rowntree, 2001, p.1). Secondly, some young carers viewed school as an “escape” from their caring role (Szafran and Duerksen, 2012, p.14). Thirdly, not all young carers had their education impacted on by their caring role (Scottish Youth Parliament, 2014; Sempik and Becker, 2014a; Family Action, 2012; Evans and Becker, 2009). Fourthly, young carers were described as ambitious about their futures- they have dreams and goals (Cass et al., 2009; Children’s Commissioner for Wales, 2009; Dearden and Becker, 2000; Evans and Becker, 2009). Finally, despite experiencing problems caused by their caring role, young carers are engaging in Higher education and doing well (Sempik and Becker, 2014a; Dearden and Becker, 2000).

The majority of literature instead outlined how a young person’s caring role could have a negative impact upon their education. How caring was reported as impacting on a young persons’ education in a negative way can be categorised under the following headings: lack of understanding and support; problems balancing their caring role and caring as their priority; concentration and behavioural problems; worry and stress; tiredness; problems with peers and social isolation; bullying and stigma; absence and lateness; less time to study and problems with schoolwork; exams and low grades; dropping out; financial hardship and poverty; and young carers and their future. The literature identified young carers as acknowledging the importance of education as something that would improve their future (Cass et al., 2009; Evans and Becker, 2009).

Differing levels of impact were identified in relation to the age of the young carer regarding how they felt about their caring role (Hamilton and Adamson, 2010; Cass et al., 2009; Revans, 2007). Young carers aged eighteen to twenty-five were described as being more frustrated by having to balance their education and caring role than those young carers aged seven to seventeen who were “less concerned” about the impact of their caring role on their education (Hamilton and Adamson, 2010, p.4).

Young carers are experiencing varying levels of understanding and support. Levels of understanding were recorded as differing between individual teachers

and schoolwide (Hamilton and Adamson, 2010). Some young carers reported being punished for issues directly linking to their caring role (Family Action, 2012; Barnardo's, 2006). They also expressed disappointment about the lack of support they received when teachers were aware of their caring responsibilities (Cass et al., 2009). This highlights the importance of establishing the extent of how young carers are being supported in education and how this links to academic achievement.

3.4 Overall conclusions – peer-reviewed and non peer-reviewed literature review

A review of literature on young carers aged sixteen to twenty-four and their education identified young carers as having a mixed experience of school (both positive and negative) with varying degrees of impact upon their education ranging from no impact to severe impact. Links have been made about how a young carers age can affect how they feel about the impact of their caring role on their education, and to young carers caring for someone with a specific condition being more susceptible to experiencing difficulties. Young carers have been presented as having positive attitudes towards their education, as wanting to do well and recognising the importance of education for their future plans.

Literature outlining the positive aspects of young carers and their education were in the minority. The positive aspects detailed included the learning of practical skills through their caring role, school being viewed positively as a sanctuary from caring responsibilities, not every young carer reporting their caring role as impacting on their education, despite their caring role young carers are ambitious about their futures and that they are engaging in higher education and achieving.

It was well documented in both the peer reviewed and non-peer reviewed literature the negative impacts being experienced by young carers aged sixteen to twenty-four on their education because of their caring role. How their caring role was identified as impacting on their education can be categorised under the following headings; an adult role at home and a child in school, absence and lateness, dropping out, problems balancing education and their caring role,

behavioural problems, concentration and tiredness, lack of understanding and support, confidentiality and intrusiveness, problems with peers, bullying stigma and isolation, lack of recognition, identification, worry and stress, financial hardship, poverty, hunger, less time to study, problems with homework, schoolwork and extracurricular activities, exams, low grades, young carers and their future.

The peer reviewed and non-peer reviewed literature were in agreement over the recommendations needing to be made to help support young carers in education.

They agreed that:

- Young carers need to be involved in formulating policy and practice best suited to support them in education (McAndrew et al., 2012; Aldridge, 2008; Warren, 2007).
- Schools must be recognised and utilised as “key sites for identifying and supporting young carers” (Bjorgvinsdottir and Halldorsdottir, 2014; Szafran and Duerksen, 2012; Robotham et al., 2010; Finnerty and O’Connell, 2009; Hill and Thomson, 2009, p.13; Warren, 2007; Thomas et al., 2003; Coombes, 2001; Watson, 1999, p.40).
- A member of staff should be identified as a contact for young carers to go to for support (McAndrew et al., 2012; Robotham et al., 2010; Cass et al., 2009; Moore and Morrow, 2007; Warren, 2007; Barnardo’s, 2006; Underdown, 2002; Watson, 1999).
- Training staff was a vital part of raising awareness about young carers in schools (Stamatopoulos, 2015; Family Action, 2012; McAndrew et al., 2012; Smyth et al., 2011; Hill and Thomson, 2009; Gray et al., 2008; Warren, 2007; Barnardo’s, 2006; Underdown, 2002; Watson, 1999).
- Education professionals need to be educated/advised and equipped with the knowledge they need to know how to act towards and support those young people identified as a young carer (McAndrew et al., 2012; Robotham et al., 2010; Alyward, 2009; Morgan, 2006; Thomas et al., 2003, Underdown, 2002).
- Educators need to treat young carers with understanding (Stamatopoulos, 2015; McAndrew et al., 2012; Smyth et al., 2011; Gray et al., 2008; Warren, 2007; Underdown, 2002).

- Formal support services need to be in place to limit the impact of a young person's caring role on their education- for example respite care for the person they are looking after (Hamilton and Adamson, 2013; Heyman and Heyman, 2013; Pakenham and Bursnall, 2006; Moore, 2005).
- Schools need to formulate and implement young carer specific policies and practices to proactively identify and support young carers (Bjorgvinsdottir and Halldorsdottir, 2014; Family Action, 2012; Hill et al., 2011).
- Schools need to work with young carer organisations/services to support young carers and to help raise awareness about young carers (Stamatopoulos, 2015; Family Action, 2012).
- Young carers need to be given flexibility towards their education by teachers (McAndrew et al., 2012; Waugh, 2012; Smyth et al., 2011; Robotham et al., 2010; Alyward, 2009; Cass et al., 2009; Hill and Thomson, 2009; Roberts et al., 2008; Warren, 2007; Morgan, 2006; Moore, 2005). Ways in which flexibility would be exercised include; use of home schooling (Cass et al., 2009, p.76), special consideration (Fives et al., 2013, p.55) and "personalised packages of learning" based on a young carer's needs and talents (Warren, 2007, p.144).
- Young carers need to be supported in a practical way at school. An example of a practical method of support agreed on was access to a telephone (Cass et al., 2009; Underdown, 2002). Also agreed was ways of giving young carers additional practical help with their education through school such as homework clubs (Underdown, 2002), study support (Warren, 2007), help obtaining notes from lessons missed (Underdown, 2002), tutoring for young carer's (Waugh, 2012) and breakfast and lunch programmes (Waugh, 2012).
- There is a need for the formal recognition of the skills and experiences young carers gain through their caring role, rather than focusing only on the negative impact of their caring role on their education (Heyman and Heyman, 2013; Finnerty and O'Connell, 2009; Moore and Morrow, 2007).

The peer reviewed literature in addition to the recommendations above, identified the need for early intervention (Hamilton and Adamson, 2013).

The non-peer reviewed literature also made additional recommendations to those outlined above such as schools having a counsellor to identify and support young carers (Waugh, 2012), and encouraging young carers to participate in further education by using “retention programs” to support them during their time at university (Peel and Beckley, 2015, p.377). An onus was also placed on local authorities and government. It was recommended that local authorities should develop and promote strategy for young carers to be supported both inside and outside of education as well as encouraging partnership working between schools and local young carers organisations (Family Action, 2012). Recommendations for government centred on legislation being introduced that made it schools “duty” to identify and support vulnerable pupils such as young carers and in addition provide adequate respite/support services for the cared for person so that a young person can access and participate in education (Family Action, 2012; Moore, 2005). This literature also suggested that in those instances where a young person is significantly affected by their caring role, there is a need for the traditional methods of intervention sometimes used and young people’s perception of such interventions to be addressed (Aldridge and Becker, 1993). It was proposed that young carers feared their families being split up should they ask for help, addressing young carers perceptions of what could happen when they ask for support would help to address these fears (Aldridge and Becker, 1993).

Reviewing the literature identified several gaps in research which justify the need for further research to be engaged in regarding the educational impact of young carers aged sixteen to twenty-four years old in Northern Ireland. These gaps can be categorised as follows; a lack of research on the educational impact of young carers aged sixteen to twenty-four years old in Northern Ireland, little empirical evidence on the impact on a young carers education, questions being raised about whether a young person’s caring role is the cause of educational problems, research predominantly focusing on the secondary school environment, a link between gender and a caring role and a link between how a classroom is organised and the identification of young carers. Each of these will now be outlined individually.

There is a lack of relevant research on the experiences of young carers in education aged sixteen to twenty-four years old in Northern Ireland. The

academic research returned by the systematic search returned two articles with a link to Northern Ireland which on further examination contained no Northern Ireland specific information, emphasising the need for a study focusing specifically on the educational experiences of young carers aged sixteen to twenty-four years old in Northern Ireland (Manderson and McCune, 2004; Roche and Tucker, 2003).

There is little empirical evidence in regard to issues surrounding young carers and their education; for example, in relation to young carers grades or levels of absence (Newman, 2002, p.613). During the review of peer reviewed documents it was common that research findings were not quantified or evidenced by statistics with general terms such as “most” and “several” being used instead (Bjorgvinsdottir and Halldorsdottir, 2013; Eley, 2004; Gates and Lackey, 1998). Qualitative research was engaged in to gauge impact on education rather than quantitative research, making it difficult to measure the extent of impact on a young person’s education. Champlain (2012) commented that “[t]he impact of academic performance and attendance would be more powerful to be data form rather than via self-reports as participants may underreport absences or not disclose poor grades” (Champlain, 2012, p.38). This highlights the need for quantitative research methods to be used and empirical evidence to be collected to research the educational impact on a young carers education in a way that is measurable and therefore comparable. Once empirical data is collected on the impact of a caring role on a young person’s education it can also be utilised to examine the variations and links between elements, for example the level of understanding and support experienced by young carers and the numbers of young people saying that their education has been impacted in a negative way by their caring role.

The absence of empirical evidence on the impact of a caring role upon a young person’s education raised the question over whether it was in fact the young person’s caring role that was impacting on their education or, was it because of other factors not linked to their caring role such as being a teenager or experiencing poverty and or social exclusion (Aldridge, 2008; SCIE, 2005; Newman, 2002). This reinforces the need for the use of quantitative research methods that present results which can be measured and compared to establish what is actually impacting on their education.

The research retrieved focused primarily on young carers in a school environment and identified the issues experienced by young carers aged sixteen to eighteen years old. Limited information was given about young carers in different educational establishments such as further education colleges, universities and training schemes and few reasons were outlined as to why some young carers were classified as being NEET. In order to identify the level of impact their caring role has upon their education and support young carers in education aged eighteen to twenty-four years old; further research is required.

Research in the rest of GB and in several African countries has identified a link between gender and those young people whose education is impacted by them having caring responsibilities (Barry et al., 2011; Skovdal, 2011; Evans and Becker, 2009; Robson et al., 2006; Lewis and Meredith, 1988). It would be interesting to see whether there is a similar link between gender and those young carers aged sixteen to twenty-four in Northern Ireland having their education impacted on by their caring role.

It has been suggested that aside from young carers being hesitant or fearful to identify themselves as such to their teachers, or teachers misreading or missing the signs that a young person may have a caring role, young carers are not being identified because teachers do not have the time or opportunities to talk to children in their class about their home situation (Szafran and Duerksen, 2012; Robotham et al., 2010; Watson, 1999). Further research into why young carers believe they have not been identified by their place of education would be useful to inform those in education, planning about the way classrooms are organised (Szafran and Duerksen, 2012).

Reviewing the relevant literature has identified contradictions and differing viewpoints which suggests a complex range of individual factors are likely to influence the experiences of each young people. Greater understanding of how home life, school life, and the young person themselves all intersect will provide a stronger evidence base for developing interventions and policies to better support young people who have caring responsibilities.

4.0 Methodology

4.1 Overview of the research approach

At the outset of the research, a protocol was developed to conduct a systematic review of literature relating to young carers and their education. Subsequently, a comprehensive consultation of peer reviewed and non-peer reviewed literature was undertaken (see section 3.0). Informed by this review, the research questions were established and refined. They are:

1. What are the educational experiences of young carers aged 16-24 in Northern Ireland?
2. How has the caring role impacted on their experience of education and/or career prospects?
3. What help did young carers receive to support them in their education and how can they be supported to fulfil their educational potential?
4. How does the educational experience of being a young carer in NI compare with GB and elsewhere?

The research approach and most appropriate data collection instruments were determined following the review of relevant literature and identification of gaps in existing research. Three research strands were developed to answer the research questions, which will be described in detail in this chapter. These were;

1. A survey of young people with caring roles.
2. Interviews with professionals working with young people in caring roles
3. Interviews with young people in caring roles.

Research instruments were devised and piloted; ethical approval was granted by the University Research Ethics Committee (UREC) in August 2017 and by Barnardo's in January 2018 (who required the researcher to submit a separate ethics application). (See section 4.6.4 Accessing young people and professionals for the study to explain the role of Barnardo's).

The process of data collection was not in reality a linear process. Difficulty in accessing young carers involved an extended data collection period, so while surveys were being circulated and completed, semi-structured interviews took place with the professionals working with these young people.

4.2 Research paradigm

Research in social sciences focuses on “...the social relationship between individuals and the social world and how and why the social world is and becomes as it is” (Matthews and Ross, 2010, p.19). Research paradigms provide ways of “looking at the world, different assumptions about what the world is like and how we can understand or know about it” (Cohen et al., 2018, p.8). They can facilitate the clarification and organisation of thoughts concerning the research (Cohen et al., 2018; Newby, 2014). Knowledge for researchers’ is mostly regarded as partial, due to the nature of the social world and their position within it. There are, however, different interpretations concerning the nature of the social world and what can be known about it. Subsequently, different stances or positions exist “on the claims that can be made about the knowledge gained from studying it” (Matthew and Ross, 2010, p.23).

Ontology, refers to the view that is held on the nature of reality and provides a framework through which to describe relationships between entities, the social world and social phenomena. (Punch, 2014; Matthew and Ross, 2010). There are three main schools of thought - objectivism, constructivism and realism. Objectivism maintains that social phenomena in the social world “have an existence of their own”, independent of, and apart from the humans involved (Matthew and Ross, 2010, p.24). Constructivism upholds that social phenomena “are constructed by people in, and through, their actions, rather than existing independently of those actions” (Becker et al., 2012, p.393). Realism contends that the social world is separate to and has a reality separate from the social actors included in it, and can be “known through the senses as well as the effects of hidden structures and mechanisms” (Matthew and Ross, 2010., p.26).

Epistemology concerns the relationship between the researcher and reality, that is, how things are known and the theory of knowledge (Punch, 2014; Matthew and Ross, 2010). There are three epistemological positions: positivism, realism and interpretivism, each offering different ways of approaching a topic. A positivist position assumes that knowledge of social phenomena is based on what can be seen and recorded; commonly, it seeks to test a hypothesis created from existing theories (Matthew and Ross, 2010). Realism presumes that the knowledge of social phenomena is formed on what can be seen and recorded as well as the “‘hidden’ structures and mechanisms whose effects can be observed” (Matthew and Ross, 2010, p.29). Interpretivism focuses on gaining knowledge from peoples’ understanding and interpretation of social phenomena; theory is then generated from the information gathered.

This research is based on a constructivist ontology that social phenomena is constructed by and through the actions of the entities involved. It is located within an interpretivist epistemology because it is concerned with understanding the world (the experiences of young carers in relation to their education) from the subjective experience of individuals (young carers and professionals) and uses methods of data collection and analysis that support this.

Alongside considerations about the ontology and epistemology of the research, a research paradigm was selected. The interpretivist or constructivist paradigm is described as portraying the world as ever changing, complex and socially constructed. In contrast a positivist paradigm assumes “a fixed measurable reality external to people” (Tuli, 2010, p.103). This research is based within a “pragmatist paradigm”, this is an approach that focuses on answering the research and delivering “useful answers to questions put by the research” (Cohen et al., 2011, p.23).)

4.3 A mixed-methods approach

A mixed-methods approach is empirical research involving “the collection and analysis of both qualitative and quantitative data” (Punch, 2014, p.302). It is described as being “based on the criteria of fitness for purpose and applicability,

and regarding 'reality' as both objective and socially constructed" (Cohen et al., 2011, p.23). Sitting within a "pragmatist paradigm", a mixed-methods approach allows the researcher to address his/her research questions using whichever methods are best suited to, and will enrich the quality of, the research (Cohen et al., 2011, p.23).

Both the quantitative and qualitative approaches used in this study were given equal weight during the design and implementation of the research instruments (Cohen et al., 2011). Quantitative research (surveys) took place with young carers co-currently as qualitative research (interviews) with professionals from young carers organisations. The qualitative aspect of research with young carers was carried out after the quantitative research was completed. Quantitative data was analysed before the coding and analysis of qualitative data. Common themes were then sought between the two data sources.

A mixed-method approach was adopted for this research primarily because a systematic review of peer reviewed studies revealed over half the studies identified used only one method of data collection and just over a quarter (26%) using two methods. The use of methodological pluralism means that any errors made when using a single approach can be identified and addressed; it therefore acts as a checking mechanism (Flick, 2014; Cohen et al., 2011). A mixed method approach enhances the response to questions such as what, how or why, which are of particular importance if the researcher "is really to understand the different explanations of outcomes" (Cohen et al., 2011, p.25). It leads to the collection of rich data, allows for "meanings in data to be probed", corroborated and triangulated (Cohen et al., 2011, p.23), and for findings to be determined by research questions rather than the theoretical preferences of the researcher (Ibid). In relation to findings, a mixed methods approach provides "more nuanced and authentic accounts than single methods approaches" and "enable a more comprehensive understanding of phenomena to be obtained than single method approaches" (Ibid, p.24). Flick (2014), cautions against a mixed methods approach that "often end up in a one-after-the-other...side-by-side...or a dominance" approach of one or other method (Flick, 2014, p.36). Instead, the research design should be formulated to guarantee integration of approaches so that bias does not occur (Flick, 2014).

A mixed-method approach was used to triangulate findings and cross check data to increase the credibility and confirm the robustness of the findings (Becker et al., 2012). In the case of this research, the qualitative data allowed the “elaboration or enhancement of the quantitative data gleaned” (Becker et al., 2012, p.130). Theoretically, the quantitative dimension of this study facilitated the qualitative research in the sense that it sought to recruit a purposive sample of young carers willing to participate in a semi structured interview (Becker et al., 2012). In practice, only a small number of interview participants were recruited this way and professionals from young carers projects were instrumental in recruiting young carers to participate in interviews. Having a quantitative element to this study ensured measurable evidence about the educational experiences of young carers aged 16-24 in Northern Ireland, a hitherto under-reported area. To date, in general, there has been limited empirical, measurable evidence collected about young carers (Champlain, 2012, p.38; Newman, 2002, p.613; Lackey and Gates, 2001). Newman (2002) argued that there is little empirical evidence to corroborate claims about young carers that do not have a direct link to impairment or illness. Instead, where concerns have arisen they are related to parenting problems, poverty or social exclusion (Newman 2002). Specifically, in relation to assessing academic performance and school attendance, measurable evidence has not been readily gathered (Champlain, 2012; Lackey and Gates, 2001). Having such measurable information being preferable to the self-reporting of participants who “may underreport absences or not disclose poor grades” (Champlain, 2012, p.38). Therefore, using both a qualitative and quantitative approach ensured different themes were dealt with within the one research project. Ultimately within this study, the use of qualitative research instruments enhanced the quantitative instruments and vice versa (Becker et al., 2012).

4.4 Surveys

Surveys enable researchers’ to engage a large sample of participants in a way which is time efficient (if using self-administering surveys) and cost effective (outlay only for printing and postage). They are, however, dependent on participants having the capability, motivation and time available to respond (De

Vaus, 2014; Fink, 2013). The information gathered is reliant on the quality of the questions it contains (Sapsford, 2007; Munn and Drever, 1995). It is important that a survey is well designed as it could lead to the collection of “superficial” information that describes rather than explains participant responses (Munn and Drever, 1995, p.5). A survey that does not explicitly ask for additional detail has been described as a missed opportunity to prompt for further details (Sapsford, 2007; Munn and Drever, 1995).

Self-administered surveys do not permit “ad hoc assistance” to respondents (Sapsford, 2007, p.121) since generally the researcher is not present to explain the meaning of questions (Munn and Drever, 1995). Respondents need to be motivated to complete and physically return a survey and there is potential that respondents may see it as an onerous task (Fink, 2013).

Rates of non-response are described as a “colossal problem” of self-administered surveys (Sapsford, 2007, p.122). De Vaus (2014) has suggested it is typical for surveys to receive a poorer response rate than personal or telephone interviews (De Vaus, 2014). Some potential participants may be reluctant to be involved, others may not be contactable and some returned surveys may not be viable due to respondent error or errors in the survey design (De Vaus, 2014; Sapsford, 2007).

In relation to the cost-efficiency of self-administered surveys, it has been cautioned that “we pay for this cheapness” in two ways (Sapsford, 2007, p.122). Firstly, if a survey is not completed in controlled conditions, such as in a classroom environment, it cannot be guaranteed “quality attention” (Sapsford, 2007, p.122). Secondly, there is no way of being certain who actually completed the survey - whether it was completed by the intended person (Sapsford, 2007, p.122). Each of these issues have potential to affect the validity of any information received. Section 2.4 outlines the steps that were taken to maximise survey returns when implementing the survey.

4.5 Interviews

Overall, qualitative interviewing requires more intense listening than normal conversations, a respect for and curiosity about what people say, a willingness to acknowledge what is not understood and the ability to ask about what is not yet known (Rubin and Rubin, 2005).

Qualitative interviews can be described as conversations guided by the researcher in a protracted discussion. Rubin and Rubin (2005), describe an interviewee as a “*conversational partner*” to highlight the active role they take influencing and steering the path of the research (p.14). The term also suggests the interviewee is an amiable and willing participant, with both the interviewee and interviewer working together to reach a joint understanding. Rubin and Rubin (2005) comment that viewing an interviewee in this way reminds the researcher “that the direction of the interview is shaped by both the researcher’s and the interviewee’s concerns”; in addition, it also serves to emphasise the individuality and distinctiveness of each person, the knowledge they possess and the unique way they interact (p.14).

Interviews can differ in flexibility, ranging between structured, semi-structured and unstructured, each with particular strengths and limitations (Grieg et al, 2013). A structured interview allows individual participants to be asked identical questions in the same way; making them efficient to conduct and enabling straightforward comparative analysis (Grieg et al, 2013; Gillham, 2005). This type of interview restricts the researcher with its lack of flexibility and makes the “assumption that the researcher already knows what the relevant questions are and only has to ask for answers” (Grieg et al, 2013, p.161). They have also been described as leading to data that is “often superficial” (Gillham, 2005, p.87). In contrast, an unstructured interview allows more scope for both interviewers and interviewees to develop their thoughts. For the researcher this freedom of questioning is a useful mechanism to explore the subject matter; however, due to its fluid structure, they can take a greater amount of time to complete and it can be challenging to keep interviewees on track (Gillham, 2005). A semi-structured interview, a hybrid of structured and unstructured interviews, has been described as the “most commonly encountered format in research” (Grieg et al,

2013, p.160). Researchers' using this method have a pre-designed interview schedule with prompts but also has the freedom to pursue an emerging discussion point that they feel is relevant. This approach allows for follow up questions "to gain clarity and precision" (Rubin and Rubin, 2005, p.14). As an interview technique, it is "costly in time" both during interviews and afterwards with transcription. It requires the researcher to develop and pilot their questions in advance and is reliant on the skills of the researcher to extract relevant information through direct and follow up questions (Gillham, 2005).

4.6 Study participants

4.6.1 Inclusion criteria

"Define your population clearly, so that anyone could judge exactly who belongs within it and who does not" (Munn and Drever, 1995, p.18).

The researcher is keen to emphasise that not all young people living with a sick or disabled relative are young carers (SCIE, 2005). The inclusion criteria for young people taking part in this study was that they were aged between sixteen to twenty-four years old, a resident of Northern Ireland and had a caring role/caring responsibilities within the family home for a family member with a chronic health condition, physical disability, learning disability, mental ill health, alcohol/drug misuse. Young people were excluded from this study if they had a caring role and poor mental health, were not identified as young carers in Northern Ireland or if they had a caring role for someone other than a family member living with them. Young carers with poor mental health were omitted as a safeguarding mechanism from any unnecessary stress. The inclusion criteria for professionals was that they currently worked in an organisation that provided support to young carers and had experience working with young carers in Northern Ireland. Young carers within this age range were chosen for several reasons. Firstly, there is an identified lack of quantifiable data relating to young carers and their education; within this age range it is assumed that most young people will have completed GCSE's thereby providing quantifiable data

(Champlain, 2012; Newman, 2002; Lackey and Gates, 2001). Secondly, this age range of young carer has not previously been of specific focus in Northern Ireland. Finally, since a study of this group has been completed in England, Scotland and Wales by Sempik and Becker (2013a; 2013b), the Northern Ireland data would serve as a source of comparison.

4.6.2 Sample size

To address the research questions appropriately, the researcher sought to invite between one hundred and one hundred and twenty young carers to complete a survey and to recruit approximately fifteen to twenty young carers and the same number of professionals for interview.

Census figures for Northern Ireland indicate that young carers represent a small and potentially under-reported population. Traditionally, they have been a hard to reach group so the researcher anticipated the sample could potentially be small even with steps to maximise access.

The systematic literature review had already demonstrated the variety of sample sizes in other research - ranging from one person to 1391 young carers (Diaz et al., 2007; Coombes, 2001). This showed the varying nature of numbers recruited by previous studies and illustrated how recruitment was often dependent on initial access to participants.

4.6.3 Sampling approach

A non-probability, purposive sample was utilised in the first instance to recruit young carers and professionals with snowball sampling subsequently used to increase the number of participants in both groups.

Fink (1995), wrote that when researching hard to reach groups;

Implementing a probability sampling method among this population is not practical because of potential difficulties in obtaining co-operation from and completing interviews with all eligible respondents (Fink, 1995, p.33).

Due to the sensitive and hidden nature of caring and the corresponding difficulties in identifying and accessing participants, non-probability purposive and snowball sampling were the most appropriate approach. A purposive sample was chosen for a specific purpose in this study, young carers aged sixteen to twenty-four living in Northern Ireland who were receiving support from an associated organisation and professionals working with this group were purposively identified to participate (Cohen et al., 2011). Using purposive sampling in this study to access professionals, enabled the researcher “to acquire in-depth information from those who are in a position to give it”- in this case professionals working with young carers (Cohen et al., 2011, p.157).

Such a sampling method is both “selective and biased” (Cohen et al., 2011, p.157; Fink, 1995). It does not guarantee that all young people providing a caring role have an equal opportunity for inclusion (Fink, 1995, p.32). In this study, it meant that, from the outset, several sub-groups of young carers would be excluded. This included any young people identified as a young carer (by themselves, their family or by a professional) who did not wish to be referred to a support organisation; young carers referred to a support organisation but on a waiting list and any young carer with poor mental health.

4.6.4 Accessing young people and professionals for the study

The researcher’s professional knowledge identified young carers’ organisations in Northern Ireland and searches were also carried out online to confirm these organisations remained operational and that no new agencies had been established since 2015 (when the researcher left work to commence full time study). Three organisations were identified: Action for Children, Barnardo’s and Crossroads NI.

Initial contact with Action for Children and Barnardo's was made via an email briefly outlining the research project and requesting a meeting. Following several emails to Action for Children a relevant staff member was identified and this same staff member subsequently provided details of their counterpart at Barnardo's. The researcher previously worked as Young Carers' Manager for Crossroads NI and made contact through the Chief Executive Officer.

Meetings took place with professionals in each organisation. During these meetings, an information sheet containing a brief summary of the title and purpose of the study was distributed. As a preliminary conversation, a series of contextual topics were covered:

1. Background to the organisation.
2. Services offered to young carers.
3. Service delivery and the involvement of young people in their design.
4. The geographic areas covered by the organisation.
5. The approximate number of young carers aged sixteen to twenty-four accessing services.
6. The researcher's background, professional experience and motivation for undertaking a PhD.
7. The purpose of the study and the underpinning research questions.
8. What participation in the research entailed.

After meeting with a representative of each organisation and obtaining initial verbal agreement of access to young carers, each professional was asked to confirm their consent in writing.

4.6.5 Young carers organisations in Northern Ireland

The Northern Ireland Regional Young Carers Service, commissioned by the Health and Social Care Board (HSCB), is contracted to Action for Children and Barnardos. These two organisations offer a service to young carers across all of Northern Ireland.

Crossroads Young Carers Project is the only other voluntary provider to young carers in Northern Ireland and is a charity project of the domiciliary provider Crossroads Care NI.

4.6.5.1 Action for Children

Action for Children has provided services to young carers in Northern Ireland since 2008. It focuses on young carers aged between the ages of eight and eighteen years and, funded by the HSCB, it resides within the Belfast Trust, South Eastern Trust and Southern Trust.

Depending on individual needs, young carers can receive support ranging from bi-monthly and monthly activities, as well as weekly one to one sessions. The type of support offered includes “a break from caring; a listening ear; individual support; information about illnesses; peer support groups; personal development groupwork programmes; advocacy, advice and signposting; fun social activities; a voice; a safe environment to express concerns and worries”.⁶⁸

In June 2017, Action for Children were providing a service to two hundred and thirteen young carers in Northern Ireland - one hundred and thirty-one females and eighty-two males. Thirty-five of these young people were aged between sixteen and twenty-four, therefore meeting the inclusion criteria of this study. As of June 2017, Action for Children also had a waiting list of twenty-nine young

⁶⁸ Handout on NIRYCS- Northern Ireland Regional Young Carers Service- Action for Children and Barnardos Northern Ireland.

people for their service and there was an eight to ten week wait from initial referral to the allocation of a key worker.

Action for Children in Northern Ireland currently have funding for their Young Carers Service to employ four full-time support workers, two part-time support workers and three casual workers.

4.6.5.2 Barnardo's

Barnardos have provided services to young carers in Northern Ireland since 1996. The service supports young carers aged eight to seventeen living in Northern and Western Trust areas and is funded by the Health and Social Care Board.

Young people can access monthly group outings and individual support when they require it. Barnardo's provides similar support services as Action for Children.

In June 2017, Barnardo's were providing a service to two hundred and thirty-seven young carers in Northern Ireland - eighty-eight males and one hundred and forty-nine females. Fifty-nine of these young people were aged between sixteen to twenty-four and therefore meeting the inclusion criteria of this study.

As of June 2017, Barnardo's had a waiting list of sixty-nine young people for their service and at this time employed six support workers.

4.6.5.3 Crossroads Young Carers Project

Crossroads Young Carers Project has provided a service to young carers in Northern Ireland since 1994. The service supports young carers aged from five to twenty-four years old living in Belfast, North Down and Ards, Down, Lisburn, Craigavon, Newtownabbey, Carrickfergus, Ballymena, Magherafelt and Ballymoney. This project is funded through the charity's fundraising efforts.

Crossroads Young Carers Project offers monthly outings as well as one-off and project-based activities several times a year.

In June 2017, Crossroads Young Carers Project were providing a service to one hundred young carers in Northern Ireland - forty-four males and fifty-six females. Thirty of these young people are aged between sixteen to twenty-four years old and therefore met the inclusion criteria of this project. As of June 2017, it had three hundred and twenty-four young carers on a waiting list. Fourteen support workers are employed part-time to provide the services.

Table 10: Numbers of Young Carers aged 16-24 Receiving a Service from Action for Children, Barnardo's and Crossroads Young Carers Project in June 2017

Age of Young Carer	Action for Children Number of Young Carers this Age Receiving a Service	Barnardo's Number of Young Carers this Age Receiving a Service	Crossroads Young Carers Project Number of Young Carers this Age Receiving a Service
16	16	36	6
17	2	26	7
18	7	0	5
19	0	0	7
20	0	0	4
21	0	0	0
22	0	0	0
23	0	0	0
24	0	0	1

Total Overall	35	59	30
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Table 10 provides a breakdown of the numbers of young carers aged 16-24 receiving a service from the three young carers organisations in Northern Ireland. These figures highlight that within the 16-24-year-old age bracket, the majority of services are provided to those aged 16-18.

4.7 Survey design

4.7.1 Developing the survey

Prior to the formulation of the self-administered young person's survey, the YLT survey outlined in Chapter Two and a manual used by young carer's organisations were consulted (Joseph, et al., 2009).

The YLT survey provided the researcher with an example of survey questions designed to establish a general picture about the lives of young carers in Northern Ireland and limited information on the impact of their caring role upon their education. In both 2010 and 2015 in addition to asking general questions on their caring role, respondents to YLT were asked to respond to the following education related statements: *I am unable to attend any out- of- school activities due to my caring responsibilities; I never miss school because of my caring role and Caring doesn't affect my schoolwork*. These same statements were not explicitly used in this research however the essence of them were touched upon, for example: *My caring role has not impacted on my education; Because of my caring role I have had to take time off from my place of education and My caring role stops/stopped me participating in extra-curricular activities*.

This research needed a survey to be designed that focused on establishing background information about young carers and their caring role like that established by YLT2010 and YLT2015 but unlike these YLT surveys the primary

focus was to establish background information about young carers situations for context and focus extensively upon their experiences of education and whether or not their caring role had impacted upon it.

Also consulted prior to the formulation of the self-administered young person's survey, was a manual used by young carers organisations (Joseph et al. 2009). This manual was formulated to; "...provide researchers and practitioners...with relevant and accessible instruments of caring activities and caring outcomes in children and young people" (Joseph et al., 2009, p.1). It outlined two instruments for the assessment of caring: *The Multidimensional Assessment of Caring Activities (MACA-YC18 and MACA-YC42)*; and *The Positive and Negative Outcomes of Caring (PANOC-YC20)*. Neither of these instruments investigated the relationship between a young carer and their education. In addition, the manual includes a survey entitled *What I Like and Dislike about Caring* and a *Post Intervention Self-Assessment (PISA-CR2)*. Both of these include several general questions on young carers and their education.

Permission was granted for these four instruments to be used in their entirety. However, due to their broad range and minimal focus on education a reduced version of the instruments would lose the robustness of the original survey design (Taylor et al., 2015). For this reason, an original survey was designed to address the research questions. Informed by the systematic review of the literature, the survey covered the main themes identified in relation to young carers and education, for example lack of recognition, support and understanding, caring as a priority, absence and lateness, low grades and young carers and their future. (See Chapter 3.0) The survey design was also influenced by Bronfenbrenner's framework and questions were formed to ensure the different layers within this theory outlined in Chapter 1.0 were addressed. For example, the inclusion of questions focusing on the young carers individual immediate environments (their *micro-system*) – ascertaining details about them, their home situation and their caring role as well as seeking to identify the influence and impact of their home, family, school and support experiences within their *meso-system*.

Also included were questions about the number of siblings in the home and their age, something that is “often not addressed” (Mechling, 2011, p.30). This feature is important as it may indicate a pattern regarding gender, age or position in the family.

A self-administered survey was employed for several reasons. It gave young people flexibility in choosing to complete the survey, minimised any additional pressure/burden on them and increased the likelihood of their ongoing participation. In terms of practicality, it ensured distribution across Northern Ireland, thereby increasing sample size and maximising completed returns. Such a method has been described as “an efficient use of time” (Munn and Drever, 1995, p.2). They are potentially the cheapest way of collecting information from a large sample over any size of geographic area. Completing a survey with pen and paper can be done anywhere at any time; it is familiar to people, and respondents are not restricted from participation because of their situation or location (De Vaus, 2014; Fink, 2013; Sapsford, 2007; Munn and Drever, 1995). Additionally, respondents can participate anonymously even if they know the person carrying it out (Munn and Drever, 1995). This was of significance in this study as the researcher had worked for one of the participating organisations, and it was anticipated that she might be known to the young people and their families.

In terms of results, surveys produce “straightforward descriptive information” and if required and the document is properly designed, explanations will be sought about what is behind such feelings (Munn and Drever, 1995, p.10). All respondents are answering “standardised questions”, based on identical questions in the same order and there is no interviewer interpreting or distorting meaning (Munn and Drever, 1995).

The researcher remained acutely aware during question formulation of the need for extreme sensitivity due to the potentially sensitive nature of the subject matter. Sapsford (2007), emphasised caution against asking “a question which caused all or some of your sample distress or psychological harm” (p.40). As a means of guaranteeing this, and as a safeguard against asking unnecessary questions. The advice of Foddy (1996) was followed, namely that two questions must be considered at the design stage “...why do I need to know this?” and “...what am

I going to do with the answers?” (p.112). This approach had the added benefit of ensuring the survey was no longer than it had to be (De Vaus, 2014).

Questions were worded simply and succinctly (De Vaus, 2014; Fink, 2013; McColl and Thomas, 2000; Munn and Drever, 1995). Careful thought was given to question design due to the lack of contact between the researcher and respondent during the administering of surveys (Lloyd and Devine, 2015). Questions were divided into six sections under relevant topic headings (De Vaus, 2014; Munn and Drever, 1995). Filter questions were asked before certain sections to ascertain whether a particular question was relevant to a participant so as to avoid confusion if a section should be non-applicable to their situation. (De Vaus, 2014).

A variety of question formats was used to avoid monotony (De Vaus, 2014). Closed questions were used to ascertain specific details and as a means of gaining responses that could be quantified (Fink, 2013; Munn and Drever, 1995). Open ended questions were included to give young people the opportunity to articulate their feelings/opinions and expand on their reasons for selecting certain response options (Fink, 2013; Munn and Drever, 1995) The option ‘Other’ was given as a response to questions at the request of the University Research Ethics Committee (Munn and Drever, 1995). To add more depth and meaning to survey responses, Likert scales and ranked responses were used (Taylor et al., 2015; Fink, 2013). As a precaution “to help avoid an acquiescent response set”, positive and negative statements were included side by side (De Vaus, 2014, p.111).

4.7.2 Layout of survey

The survey contained thirty-five questions, comprising four closed questions, fourteen multiple choice questions, thirteen open questions, three Likert scale questions and one ranked question. In total, questions were spread across six sections, presented in a format that endeavoured to have a logical flow (De Vaus, 2014, p.110; McColl and Thomas, 2000. (A copy of the Survey can be found in Appendix Two).

Section one was designed to establish the details of the young person's caring role. Section two focused on the young person's education, their educational status and if they felt their caring role had impacted on the grades they had received and their future education. Section three concentrated on ascertaining whether the young person received help/support because it was known that they had a caring role for a family member. Section four was only to be completed by those young people who had identified themselves as not in education, employment or training. The purpose of this section was to learn whether the young person is not in education, employment or training by choice or not by choice. Section five concentrated on the young person's previous and current educational experiences. Section six requested information so that details about the demographics of the young people participating in the survey can be collected to enable the contextualisation of results.

4.7.3 Piloting the survey

The survey was piloted with two young carers aged 16-24 years from a young carers organisation. Survey questions were piloted to ensure that instructions were clear and that questions were well worded and not exhaustive (Fink, 2013; McColl and Thomas, 2000; Munn and Drever, 1995). Piloting also acted as a safeguard to ensure questions were "to the point" and were appropriately sensitive to the subject matter (Fink, 2013, p.95). The young people completed this via email from their young carers' organisation. One young person did not recommend any changes, remarking that it "covers everything I could think of and I don't think I could add anything to be honest". The other young person helpfully commented that "the only question that I couldn't answer would be hours per week that I care for my dad because I just wouldn't have a clue, others maybe could but I wouldn't know". Subsequently, this feedback resulted in the addition of an "unsure" option in the answer options for question five of section one.

4.7.4 Implementing the survey

Data protection protocol meant that the researcher could not obtain lists of young people from young carers' organisations; instead the organisations distributed the survey packs directly.

The three organisations provided the researcher with the total number of young carers meeting the inclusion criteria, specifying whether they were under eighteen or over eighteen years old. This enabled the researcher to collate survey packs with the relevant consent forms and information sheets labelled 'U18' (under eighteen) and 'O18' (over eighteen). These were then delivered to organisations with a reminder note on distribution, as agreed with the relevant line manager.

All paperwork was provided by the researcher. If an organisation had a freepost address, freepost envelopes were included inside the survey packs. Organisations without a freepost address had stamped addressed envelopes included in the pack, the purpose of this being to facilitate ease of return and ensure no cost to participants. Each organisation was reimbursed for postage.

Organisations agreed to write a cover letter for inclusion with the survey packs; this endorsed the research study and encouraged participation. It was anticipated that as these young people would have regular contact with the organisation, a cover letter would provide reassurance and increase the likelihood of a response (De Vaus, 2014; McColl and Thomas, 2000). Surveys were distributed between December 2017 and February 2018. Participants were asked to return their survey within four weeks from the date of postage. Reminders were issued by each organisation after two weeks to increase returns. Returned surveys were then collected by the researcher at a convenient time.

Young carers are a hard to reach and underrepresented group in research; it was envisaged that a low response rate was a real possibility so the design and administration of the survey was planned to minimise obstacles to participation (Taylor et al., 2015). To address any fear of identification, respondents were assured via the information sheet and consent form that surveys would be completed anonymously and all information treated in strictest confidence (De

Vaus, 2014; Fink, 2013; McColl and Thomas, 2000).(See section 3.4 'Ethical Considerations').Participants were made aware that the researcher was “readily available to help” answer any questions they may have, and their contact details were given (De Vaus, 2014, p.136). As a means of encouraging participation, a small incentive was offered (De Vaus, 2014; Fink 2013). A twenty pounds Post Office Voucher, was provided for each participating organisation, and the winner would be drawn from the young people participating in the survey.

Figure 5 represents the process of distributing questionnaires with each young carers organisations.



Figure 5: Questionnaire distribution process

4.8 Interview design

Interview questions were formulated based on the research questions, literature review and Bronfenbrenner's framework (See Interview Protocols in Appendix Three). The interviews carried out with young carers and professionals were semi-structured in the sense that they had pre-established questions. However, in keeping with the aim and research questions, the researcher was keen to engage in a more responsive style, particularly during interviews with young people (Rubin and Rubin, 2012). Lee (1993), wrote that interviews, by their nature, are "typically a stressful experience for both the interviewee and the interviewer" (p.102). Due to the potentially sensitive, personal nature of this topic, the researcher believed, informed by professional experience, that such a method focuses typically on what the "interviewee has experienced and sees as important in relation to the issue of the study" (Flick, 2014, p.208) and allowed for a more conversational approach (Rubin and Rubin, 2005). Despite the pre-established questions, the format was sufficiently flexible to interviewees responses (Rubin and Rubin, 2012). This was done through probing, asking for clarification and reflecting on what the interviewee was saying to gain further depth and detail (Rubin and Rubin, 2005). This approach retained "a strong element of discovery" while still allowing for "an analysis in terms of commonalities" (Gillham, 2005, p.72). The semi-structured and flexible structure of the interview corresponded well with the Bronfenbrenner framework employed in this study, allowing participants to have a greater opportunity to describe the interplay of various influences on their educational experience.

For interviews with professionals, the focus was on "their capacities as experts for a certain field of activity", in this case, their work with young carers (Flick, 2014, p.227). Due to this focus, interviews with professionals were more directed and sought to exclude topics not of relevance (Flick, 2014).

4.8.1 Piloting interview questions

Interview questions for Professionals were piloted using two staff from an organisation associated with a young carers project. These were senior managers; although both had extensive knowledge of the workings of the young carers organisation and the issues experienced by staff, they had no first-hand experience working with young carers. They suggested the addition of a question on professional qualifications to further establish the background of participants. This was added to the interview protocol for professionals.

Interview questions for young carers were piloted using two young people aged between 16-24 years old from a Young Carers Organisation. They were asked for feedback on content, clarity and sensitivity. They did not recommend any additions or amendments to the interview protocol.

4.8.2 Interviews with professionals

Thirteen professionals (from across all three young carers organisations) agreeing to participate in an interview were provided with an information sheet and consent form (see Appendix Four). To minimise inconvenience, interviews took place at a time and location that was convenient between December 2017 and February 2018 and during March 2019, with each professional choosing to be interviewed at their office. Prior to starting each interview, the researcher established if the professional had any questions about the study and these were addressed accordingly. They were also reminded that their participation was voluntary, that they would not be identified in the research and that reference to any specific school or person would be anonymised. Interviews were voice recorded and lasted on average around forty-five minutes to an hour.

The interview protocol for Professionals was divided into four sections containing a minimum of sixteen questions for them to answer (See Appendix Three).

Section one was designed to acquire background information about the professional being interviewed. Section two focused on ascertaining details of the professional's experience working with young carers aged 16-24 years old in Northern Ireland.

Section three concentrated on the professional's experiences of young carers and their education both negative and positive. The fourth and final section of the interview focused on, if, through their professional experience, they had identified any recommendations that could be implemented to help support young carers in education. Once interviews were concluded, professionals were thanked for participating and a follow up email was sent by the researcher.

4.8.3 Interviews with young carers

Interviews took place with young carers between July and August 2019. Young carers agreeing to participate in an interview were given an information sheet and a consent/assent form as was applicable to their situation. Participants over 18 years old were asked to sign a consent form and participants under the age of 18 years old were asked to sign an assent form, with their parent/guardian completing a consent form (See Appendix Five).

In order to minimise inconvenience to young people, interviews took place at a time and location of their choice (if over 18 years old) or at a time and place agreeable to the participant and their parent/guardian if they were under 18 years old. Interview locations included a coffee shop, a hotel reception area and the office of the young carers organisation that they received support from. Observing duty of care, for those currently receiving a service from a young carer's organisation, young carers worker was informed about the time and location of the interview. In half of the interviews, young people were accompanied by their young carer's worker; however, to preserve confidentiality, this person they did not sit in on the interview.

As was the practice at the Professional interviews, at the start of each interview with each of the six young carers, it was asked if they had any questions about the research and if so, these were addressed. They were also reminded that that

their participation was voluntary, that if they wanted to take a break at any point during the interview that was no problem, that they would not be identified in the research and should they mention a specific school/ person etc, this would be anonymised. It was explained that the interview would remain confidential unless they disclosed something that suggested they were at risk of harm or a risk to others. Interviews were voice recorded and lasted on average around thirty minutes to an hour.

The interview protocol with young carers consisted of six sections with a minimum of twenty-nine questions to be addressed, although these were not all open-ended questions (See Appendix Three).

Section one collected background information about the young person's situation.

Section two focused on whether or not they were in education, employment or training. Section three determined their overall experience of education.

Section four, was based on statements formulated from the literature review and survey questions, asking young people to respond to a list of statements.

Section five focused on the support the young person did or did not received.

Section six, asked participants to reflect on the help they had received and based on their experience what recommendations they would make to help support young carers in education. Once an interview was completed, the young person was thanked for giving of their time to participate.

4.9 Data analysis

Sections 4.9.1 and 4.9.2 will outline in detail the data analysis used for the survey and interview data. All data collected was analysed with due consideration of Bronfenbrenner's model, particularly the porous interaction of influences on a young carer's social environment. To reflect this, some influences are reported across themes, depending on the context within which they were described by young carers.

4.9.1 Analysis of the survey data

To analyse survey responses, SPSS, a statistical package for social sciences and Microsoft Word were used. For SPSS, variables were defined - their types classified, and they were labelled using 8 characters to reflect the question being asked or statement being responded to. For example, the variable label for the question *When do you provide your caring role for this/these family member(s) within your family home* was WHENCARE. Missing values were defined, and column formats set. This was completed firstly on paper and was then manually entered into SPSS creating an analytic framework for survey responses. Survey respondents were then anonymised by being labelled YC1, YC2 and so on. SPSS was then utilised to compile quantitative survey responses and as a means of obtaining averages and the frequency of variables. It enabled the collation of information to identify the themes occurring for young carers aged 16-24 in Northern Ireland. Unfortunately, due to the small number of respondents, it was not possible to perform statistical tests. The intention had been to complete cross-tabulations to look at the association and relationships between variables, for example between the hours a young carer was providing care and the impact on their education. George and Mallery (2016), wrote that a sample size needs to be “large enough to create meaningful correlations”, they emphasised that although there are “no hard rules concerning acceptable sample size...as a ‘N’ drops below 50, the validity of your results become increasingly questionable” (p.207). A similar problem was identified in PCC (2011) in relation to data collected in YLTS 2010, when the number of respondents were “too small to yield statistically significant results” (p.7).

Cronbach’s Alpha was tested for, the reliability of the scales used in Section five of the survey titled *‘Education and your caring role’*. This section contained both positive and negative statements for participants to respond to using a Likert scale, all positive statements were reverse coded to ensure the consistency of responses given (Nichols, 1999, p.4). The first test, including all 37 variables of this section gave a Cronbach Alpha of .979. The second test removed statements where answers were optional and included 35 variables, Cronbach’s Alpha remained at 0.979. The third test removed 5 statements that had a lower

response rate than the others and Cronbach's Alpha was equal to 0.976. These Cronbach's Alpha results reveal that the scales used in Section five are reliable as the closer Cronbach's Alpha is to 1.0, "the greater the internal consistency of the scale" (Gliem and Gliem, 2003, p.87).

The qualitative responses to survey questions were compiled within a Word document. When this was completed, coding of these responses followed Braun and Clarke's (2006) model (See Table 10) and was completed manually. The researcher familiarised themselves with the statements and initial codes were generated. Overarching themes and sub-themes were searched for, reviewed refined, defined and interpreted in preparation for explaining and elaborating on survey responses when writing up the findings.

4.9.2 Analysis of the interview data

Interview recordings were transcribed verbatim, should the interview participant discuss something that could, even potentially, compromise their anonymity, the relevant word was replaced with a generic term. It was also included when there was laughter during an interview, pauses or significant emphasis on a word/sentence. Once transcribed, interviews were re-listened to, to check and rectify any mistakes. Transcribed interviews were then sorted into two types, interviews with Young Carers and interviews with Professionals, as each interview type was analysed separately. To preserve anonymity, young carer interview participants were labelled YCInt1, YCInt2 and so on, and Professionals were labelled P1, P2, and so forth.

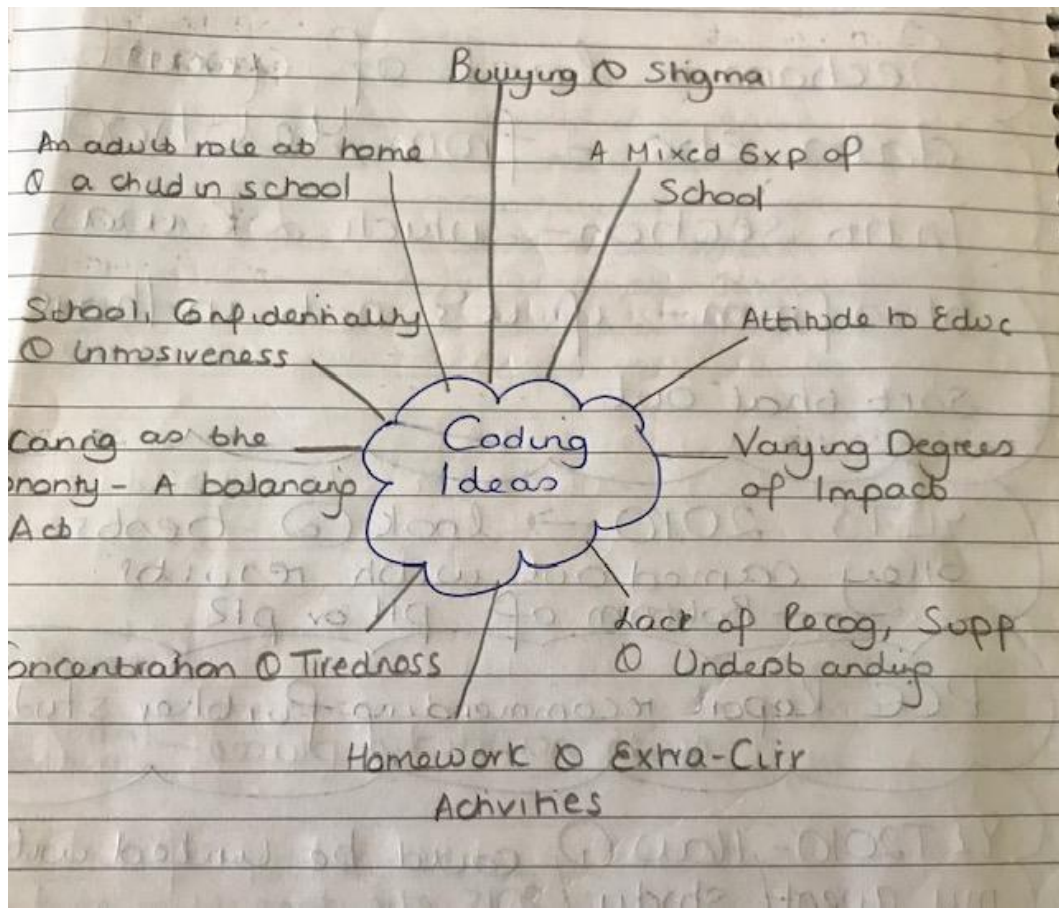
The qualitative computer data analysis program NVivo was then used to analyse information collected during interviews. Braun and Clarke's (2006) six steps of thematic analysis were used during this process. A thematic analysis was selected as it is a flexible approach "not tied to a particular epistemological or theoretical perspective" (Maguire and Delahunt, 2017, p. 3352).

Table 11: The six steps engaged in during thematic analysis based on Braun and Clarke (2006, p.88-93)

Step Number	Description
1	Familiarising self with the data
2	Initial codes generated
3	Searching for overarching themes and sub-themes
4	The reviewing and refinement of themes
5	Defining themes
6	Final analysis, interpretation and report writing

Interviews with young carers and professionals were analysed separately.

Prior to the coding process, the researcher had compiled a list of potential coding ideas, based on interview protocols and literature review (See Figure 4). These were used as a means of validating codes that were identified within the data.



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Figure 4: Example of initial potential coding ideas

Three rounds of coding were engaged in before themes were defined for final analysis. Figure 5 shows a sample of the initial codes generated during Phase One of coding, at this stage codes were generated with the knowledge that these would be further refined as the coding phases progressed. The 'Files' column relates to the number of interviews with young carers that a specific code was mentioned and the 'References' column to the number of quotations assigned to that code. Throughout the coding process, the researcher engaged in a code-recode strategy, allowing a period of time to pass between each coding round to ensure consistency and reliability (Anney, 2014).

Phase 1- Initial Code Generating

Name	Files	References
How Coped with Caring Role	1	3
Relationship between Caring Role and Education	3	6
Stigma	3	3
Friends at School Knowing about Caring Role	3	4
Current Education Status	4	18
Experience of Education	4	15
Attitude towards Education	4	5
Impact of Caring Role	4	9
Awareness of Place of Education to Caring Role	4	13
Missing School	4	7

Figure 5: Example of a number of initial codes generated

Phase two of coding focused on identifying and grouping overarching themes and sub-themes. Figure 6 provides an example of coding for an over-arching theme and the sub-themes within.

Item	Explore	Coding	Cl
Phase 2- Overarching Themes and Sub Themes			
Name	Files	References	
How Caring Role has Impacted on their Education	0	0	
Attendance	6	14	
Bullying	6	11	
Concentration and Education	6	8	
Dropping out	6	9	
Extra-Cirricular Activities	6	18	
Impact of Caring Role	6	29	
Lateness	6	11	
Stigma	4	5	
The Future and Their Caring Role	6	14	
Tiredness and Education	5	7	

Figure 6: Example of coding for overarching themes and sub-themes.

Phase three involved the reviewing and refinement of themes, an example of how sub-themes were refined within overarching themes can be seen in Figure 7.

Tiredness and Education	5	7
Resulting in time out of class	1	1
Tiredness linked to caring role	3	5
Tiredness not an issue for participant	1	1
Tiredness not because of caring role	1	1

Figure 7: The refinement of Individual sub- themes identified within overarching themes

As a method of checking that nothing had been missed during the coding process, text search queries were used to check for example, if all references had been coded for EWO's and EMA, and to search for words such as 'concentration' or 'tiredness'.

4.10 Ethical considerations

Cohen et al (2011) write;

In approaching educational research, our advice is to consider it to be far from a neat, clean, tidy, unproblematic and neutral process, but to regard it as shot through with actual and potential sensitivities (p.177).

Research ethics ensure the protection of everyone involved in the research process. Ethically, extra care needs to be taken when working with vulnerable groups such as young carers, to ensure their feelings of powerlessness is not increased. Instead, research should be formulated "to leave them untouched and in the condition in which contact was first made" (Cohen et al, 2011, p.175).

Based on guidance from the British Educational Research Association (BERA), thought was given throughout the study to ethical considerations. The principle of informed consent was applied at each stage of data collection with all participants. Participants took part voluntarily and could withdraw from the study at any time. The purpose and prospective uses of the research was fully disclosed to participants and confidentiality and anonymity were respected and protected at all times (Bryman and Becker, 2012). The subject matter of this research was

approached in a sensitive, independent and impartial way, upholding integrity (Bank, 2012; Bryman, 2012).

As this study involved a vulnerable group, it required a Category B ethics application to the University Research Ethics Committee (UREC) and approval was granted for this in August, 2017; in addition, approval was sought from Barnardo's Research Ethics Committee (BREC) and was granted in January 2018 (See Appendix Six) . The other gatekeeper organisations did not require additional ethical approval to be sought.

4.10.1 Informed consent

Informed consent was gained from all participants prior to data collection. Information sheets were distributed to all participating young carers, their parent/guardian/cared for family member and professionals. It was anticipated that the recruitment of young carers may be affected by parental reluctance to have their child participate. To ensure transparency throughout, information sheets outlined the purpose of the research and what participating involved. It also encouraged participants to ask any questions they may have and provided them with the contact details of the researcher and their supervisors. Participants were reminded that participation was voluntary and that they could withdraw at any time. To ensure content validity and that information was accessible to participants, information sheets, surveys and interviews were piloted using young carers and professionals. Details about what the research entailed was outlined again in the consent/assent section of the survey and similarly in the consent/assent form for all participating in an interview.

In line with the University Research Ethics Committee recommendations, in the cases where a participant was under 18 years old, their parent/guardian and the person receiving care (if they are over 18) were asked to give consent. The young person was also asked to give assent. Obtaining consent from a young person's parent/guardian was considered necessary because of their age and the sensitive nature of the subject matter. In cases where a parent/guardian or cared for person was unable to physically sign their consent because of 'significant

physical health problems', the person with significant parental responsibility or proxy could consent on their behalf.

4.10.2 Confidentiality and anonymity

Information provided by participants was treated as confidential unless they disclosed anything that suggested they were at risk of harm to themselves or others. Only participants and their parent/guardian or cared for family member (if applicable), the researcher, those named as investigators associated with the project (the researchers' supervisors who will see the completed consent forms) and the research ethics committee at Ulster University (should they carry out a review) will know the identity of participants who have taken part.

The limits of confidentiality were outlined in the information sheets provided to participants and their parents/guardians and/or cared for family members (if applicable) for both the survey and interview process. To maintain participants' confidentiality throughout the research the following steps were taken. Young people and professionals were interviewed individually and reminded at the start of their interview about the limits of confidentiality. No outputs relating to their participation was or will be forwarded to their home address.

Confidentiality was preserved by storing data such as completed surveys was stored in a secure location, in a locked cabinet. Any information being analysed from surveys and recordings from interviews was stored on a password protected computer accessible only by the researcher. Information was only made available to those named as investigators associated with the project (researchers' supervisors) and the research ethics committee at Ulster University (should they carry out a review). In accordance with The General Data Protection Regulation 2016/679, all data will be retained for 10 years from completion of the study. No data was destroyed during/upon completion of the project, everything has been retained and stored securely in Ulster University Archives in compliance with the universities data protection policies.

Participants are not identified in the research findings by their real name, any reference to the information they provided was anonymised. Should a quote or vignette be used from an interview with a young person or professional, a pseudonym was used to ensure anonymity of the participant. Should a professional have referred by name to a young person they work with, again a pseudonym was adopted to preserve anonymity. Participants were also not identified as specifically linked to a particular Young Carers Service/Organisation. Participants were made aware that any information they give will be treated anonymously on the information sheet provided to them.

4.10.3 Competency of researcher

The researcher has over seven years' experience working with young carers in a professional capacity. They are aware of the issues facing young carers and have significant experience dealing sensitively with these young people, their families and their individual circumstances. The researcher has attended training on research skills and research integrity at Ulster University and also received child protection training in September 2017 through Girlguiding Ulster.

The research adhered to the Ulster University Code of Practice for Professional Integrity in the Conduct of Research and has approval from the University Research Ethics Committee. This study also received additional approval from Barnardo's Research Ethics Committee. Throughout the project, the researcher adhered to each participating organisations Codes of Conduct and safeguarding policies as well as any other relevant procedures.

It is acknowledged that the research might involve young people disclosing information about a situation that is sensitive and personal to them and their families and may not be a subject they are used to discussing.

The survey and interview questions were piloted with young carers and professional's working with young carers as a means of checking, not just that they were easily understood, but also that they were sensitive to the situations of young people with a caring role. Through her professional experience, the

researcher was aware of the issues facing young people with a caring role and paid close attention to the design of the research instruments so that subject matter was phrased in a sensitive way that was considerate of the possible emotional impact on participants.

4.10.4 Safeguarding participants

To safeguard, protect and minimise distress to those young people with a caring role who may be more vulnerable to distress because of poor mental health, service staff were instructed to exclude such young people from the research sample and any others who they feel it would not be 'a good idea' to send surveys to for other personal reasons.

4.10.5 Stress protocol

Due to the sensitive personal nature of discussing a young person's caring role, should they become upset/distressed participating in the research, a Stress Protocol was put in place (See Appendix Seven). Should a young person become upset completing a survey, a supporting letter was included by the distributing young carers project/organisation informing them to contact their project worker for support. It was stressed at the beginning of interviews that the researcher would be checking in with the young person throughout the interview to check on how they are feeling. Should they become distressed, the researcher would pause the interview and check whether the young person would like to stop, take some time and come back to the interview should they wish to. Project workers were made aware in advance of any interviews to take place. The researcher had access to the relevant project workers contact number as had the young person being interviewed. Should a young person become distressed as well as taking the above steps, the researcher would inform the project worker of the young person being interviewed and their parent/guardian (if applicable).

4.10.6 Participant comfort

The researcher did not want participants to feel burdened by participating in this research. Attention was given to making participants feel comfortable and secure in the interview environment. It was important that the location of the interview was somewhere that participants and their parents/guardians (if applicable) were happy with and all arrangements were made in consultation with the young person and their parents/guardians (if applicable). To minimise inconvenience, interviews took place at a time and location of the young person and their parent/guardians' choice if they were under 18 years old or at the choice of the young person/professional if they were over 18 years old. Should a participant and their parent/guardian (if applicable) choose for an interview to take place in a public place, care was taken to make sure it was not in an open place so that they could speak to the researcher confidentially. The same principles were adhered to when interviewing professionals.

4.11 Reflexivity and the research design

Reflexivity is a “process of a continual internal dialogue and critical self-evaluation of researcher’s positionality” (Berger, 2015, p.220). Many unexpected situations have potential to arise during the research process, and it is impossible to anticipate what these may be and how they should be addressed (Guillemin and Gillam, 2004). In addition, the relationship between the researcher and researched is always intertwined “with systems of social power based on gender, sexuality, class, “race”, ethnicity, age, (dis)ability, and other factors” (Vanderbeck, 2005, p.388). However, reflexivity can act as “a sensitizing notion that can enable ethical practice to occur in the complexity and richness of social research” (Guillemin and Gillam, 2004, p.278).

Every element of this research project from the original idea to the designing of data instruments, organising practicalities of the study, interacting with participants and subsequent interpretation of the findings was informed by the

researcher's professional experience and knowledge of working in a young carers organisation, over 7 years' as a project worker and then project manager. Finlay (2002) advises researchers' even as "a project is forming" to "examine their motivations, assumptions, and interests in the research as a precursor to identifying forces that might skew the research in particular directions" (p.536). The researcher was open in her professional motivation for wanting to undertake this research and acknowledged this could lead to the potential for bias. To minimise this risk, the researcher was conscious of this potential throughout the research process; she adhered to the stipulations of UREC and BREC, used a mixed method approach and triangulated results and sought regular feedback from supervisors, (Anney, 2014, p.276).

Berger (2015), describes three advantages when a researcher is "studying the familiar", that it leads to an "easier entrée, a head start in knowing about the topic and understanding nuanced reactions of participants" (p.222). This was the experience of the researcher; however, it also raised some additional issues. Having previous experience working with young carers and their families meant the researcher had close ties with one young carers group and although it facilitated easy access to participants from this organisation. In order to address this, through openness and transparency, the researcher's background was disclosed during initial meetings with each organisation and any questions answered during informal conversations with staff members. The knowledge and experience of the researcher helped move past this potential issue and helped build rapport. As professionals in these organisations learned more about the origins of the project, the researcher found them to be supportive and enthusiastic. It was evident from the interactions with these professionals that they were genuinely interested in and wanted the best possible outcomes for the young people that they worked with.

During interviews with professionals, the researcher's background aided them to easily address the research topics and had the benefit of enabling them to recognise potential areas for further areas to probe and "ferret out hints that others might miss" (Berger 2015, p.223). During interviews with the professionals, participants would imply certain things in their responses, making assumptions that the researcher would understand what they meant by leaving sentences unfinished (Berger 2015; Drake, 2010). A researcher without the experience and

knowledge may not be as sensitized and understanding to such inferences. Finlay (2002) writes that “the self is exploited only while to do so remains purposeful” (p.542). It has been cautioned that a researcher having shared experiences with participants can cause their beliefs to be projected on to those they are interviewing as well as raising feelings of competition and comparison (Berger 2015; Drake 2010). The researcher would agree that her experience interviewing professionals was a situation in which she found herself “constantly struggling with the questions of how much to disclose, in which manner, when, and to whom” (Berger, 2015, p.224). Similarly, during the interviews with young people, the researcher found it hard at times not to react to the situations being discussed. She did however seek to be sympathetic, encouraging and positive during all interviews.

One professional from the organisation where the researcher was previously employed had been interviewed, appointed and trained by the researcher as her replacement. Interviewing this professional was challenging as the researcher had extensive knowledge about the workings of the organisation and the young people involved. The researcher dealt with this by adhering to the interview protocol and treating this interview the same as she had any other.

Every effort was made to make all participants feel at ease, some professionals and young people appeared nervous and in these instances the researcher aimed to be much more conversational to relax them. When interviews with professionals were carried out, the researcher was obviously pregnant, and this not only served as a good conversation starter but also gave the researcher further common ground with several of the interviewees.

Christie (2006) identified the potential problem of interview participants using “interview sessions to access support or therapy” (p.119). The researcher decided that should such a problem arise with any young people, they would not address them directly during the interview but signpost them back to the relevant young carers organisation they had been affiliated. This was agreed with these organisations. It was, however, not an issue during the interviews with young people.

4.12 Evaluating the research design - reliability and validity

Bryman (2012), writes that "...validity presumes reliability" (p.173).

This research can be replicated by others, from the systematic literature review to the surveys and interviews to the coding and thematic analysis of the information collected. Rigour was ensured through the use of a mixed method approach which enabled the methodological triangulation of results, which also acted as a means of safeguarding against any bias and allowed for cross examination relating to the integrity of participants responses (Anney, 2014). In addition, this research enabled triangulation to take place between the information gathered through young carers and the professionals who work with them. Triangulation was important to ensure rigour and quality of research as it corroborated the information gathered from a number of sources.

In terms of content reliability, survey and interview questions were piloted with young people and professionals (Flick, 2014; Sapsford and Jupp, 1996). Surveys and interview questions were applied consistently in every encounter (Punch, 2009). They were also based upon the findings of the systematic literature review, a rigorous review of the literature, which helps ensure that we know that these are measuring what we think it measures (Punch, 2009). The involvement of young carers and the professionals working with them gave the project credibility.

Throughout the study the researcher practiced reflexivity, reflecting on their role within the research process (See section 5.0). To ensure that the researcher's interpretation of the data was valid, a sample of the coding process was reviewed by a research supervisor and throughout the research process the researcher sought advice and guidance from their supervisors

An audit trail demonstrated how data was collected, recorded and analysed (Anney, 2014). This allows for replication of the study and demonstrates how findings and analysis were reached. Survey responses were inputted into SPSS which allowed for the tabulation of results and information collected through the surveys and interviews was triangulated (Sapsford and Jupp, 1996). NVIVO was used to code interview data and the researcher engaged in a code-recode strategy, giving a period of time between each coding so that results from codings

could be compared for consistency but also if such results are in agreement “it enhances the dependability of the qualitative inquiry” (Anney, 2014, p.278).

4.13 Limitations of the research approach

This study sought to recruit approximately fifteen to twenty young carers to interview and the same number of professionals and between one hundred and one hundred and twenty young carers to be invited to complete a survey. In reality, six young carers and thirteen professionals participated in an interview. Four Hundred and ninety-five young carers were invited to complete a survey (a substantially higher sample amount than originally expected) however only thirty-five, 7.07% were returned completed and a small sample had implications for tests on statistical significance as outlined in section 4.9.1. Retrospectively, a post on the social media account of the organisations involved may have helped yield more interview participants and survey respondents. However, the possibility of low responses had been anticipated due to the nature of the research subject and the complex lives of the individuals involved.

Due to the limited avenues to identify young carers and the documented hidden nature of this population, this study includes only those young carers known to support services who are either being currently supported or have received support due to their caring role (Mechling, 2011; Aldridge, 2008; Roberts et al., 2008; SCIE, 2005; Newman, 2002). This also meant that using random population samples was not a viable option for a small scale study.

Aldridge (2008) writes that some young people may always naturally be omitted from participating in research to tell their stories “simply because they do not want, or feel unable, to participate verbally” (Aldridge, 2008, p.262). For those young people providing care there may be additional reasons behind why they may wish to withhold information (See Literature Review).

The distribution of surveys, due to data protection, could not be done by the researcher. This was completed by the project and administration staff in the

Young Carers Organisations who had agreed to support this research. Such method of distribution was therefore dependent on staff within Young Carers Organisations having the availability of time and willingness to carry out the task. Consequently, the researcher was engaged in a process of 'chasing up' organisations to confirm that the distribution of survey packs and reminder letters had been completed. Such follow up could be time consuming and felt awkward as those helping distribute the surveys were completing this in addition to their daily workload. Their help was greatly appreciated; however, it is imagined that completing this task may not have been a priority and there was no guarantee that packs and reminder letters were posted promptly. As survey packs and reminder letters contained deadline dates, the worry was that some young people if they received a survey close to the deadline they would be dissuaded from completing it due to assuming it would not reach the return address on time.

4.14 Conclusion

Overall, although there were some limitations, as would be expected in any research project, particularly where the study participants are widely acknowledged to be a 'hard to reach' group, it is hoped that the richness of the data and the insights from the survey and interviews with young carers and the interviews with those professionals working with them, will offer a great understanding of the experiences of young carers in NI and the impact their caring responsibilities has on their education. The following chapter will present the research findings.

5.0 Findings

5.1 Introduction

The previous chapter outlined the methodological approaches chosen to explore the research questions introduced in Chapter One. The purpose of this chapter is to present the findings of the data collection process and is divided in to three sections.

Section 5.2 outlines the findings from the young carers' survey's including the background of survey respondents and details of their caring roles, the current educational status of respondents, their educational experiences and the impact of their caring role upon their education. Where respondents received support from in relation to their education and the types of support they had received from the young carers organisations they were involved with is also reported.

Section 5.3 presents the findings from interviews carried out with young carers'. Information is provided about the interviewee's backgrounds, their experiences of and attitude towards education, their experiences with teachers, the impact of their caring role on their education and their sources of support. This section concludes by reporting the recommendations these interviewees identified that would help them fulfil their educational potential. The recommendations made are categorised into those for educators and places of education and recommendations for young carers from young carers.

Section 5.4 will outline the findings from interviews with professionals. This section will present from the professional's point of view: the positive educational experiences of young carers aged 16-24 in NI; the negative experiences of young carers aged 16-24 in NI; the experiences of young carer professionals building relationships with schools and recommendations to support young carers to reach their educational potential.

The presentation of these findings is representative of Bronfenbrenner's model. For example, in relation to the survey and interview findings from young carers, these are structured by firstly focusing on the young carer's *micro-system* before discussing what is being experienced in their *meso-system*, the impact of

their *micro-system* on their *meso-system*, their sources of support and the recommendations they would make.

5.2 Findings from the young carers' survey

5.2.1 Background

Four hundred and ninety-five surveys were distributed to young people identified as having a caring role via relevant organisations in Northern Ireland. Thirty-five surveys were returned, making the overall response rate 7.07% (see section 4.13).

5.2.2 Demographic background of survey respondents

Of the thirty-five surveys returned, 54.3% of respondents were aged 16 or 17, and 45.7% were age 18 or over. Overall 28.6% of all respondents were male and 71.4% female. Geographically, responses were received from young carers from every county in Northern Ireland except County Londonderry. Although the Young Carers organisations involved in the study covered all of Northern Ireland, the majority of responses came from young carers living in County Antrim and County Tyrone (Table 11).

Table 12: Number of survey's returned from each County in Northern Ireland

County	Percentage of Survey Responses Received (N=35)
Co. Antrim	42.9
Co. Armagh	11.4
Co. Down	14.3
Co. Fermanagh	5.7
Co. Londonderry	0
Co. Tyrone	25.7

5.2.3 Respondents caring roles

The family members that respondents were providing care for were, in the following order: mother (n=35; 42.8%), brother (n=35; 40.0%), sister (n=35; 20.0%), father (n=35; 11.0%) and grandmother (n=35; 8.6%). Six respondents (n=35; 17.1%) were providing care for more than one family member.

Regarding the health condition of the person/people they were providing care to (n=35), 40.0% had a physical illness, 37.1% had a learning disability, 34.3% had a physical disability, 31.4% had mental ill health, 11.0% had either a hearing or visual impairment, and no-one provided care to someone with an addictive illness. Almost two thirds (62.9%) of respondents were providing care for someone with more than one condition.

Respondents most commonly provided care seven days a week (n=35; 77.1%) compared to the 8.6% who did this *only occasionally when required*. Almost 23.0% were unsure how many hours per week they provided care; the most frequently selected option was 6-10 hours (n=35; 20.0%). One participant revealed that they provided care in excess of seventy hours a week and another that they provided care any time that it was necessary. In total, six respondents (17.1%) identified that they were providing care over thirty-five hours a week, the equivalent of a full-time job.

The length of time each respondent provided care, is outlined in the following Table 12. Between four to five years and between ten to eleven years were jointly the most frequently selected amount of time respondents had been providing a caring role with every participant providing care for at least two years

Table 13: Number of years providing caring role (N=35)

How Many Years Providing Care	Percentage of participants
2-3	8.6
4-5	22.9
6-7	11.4
8-9	17.1
10-11	22.9
12-13	8.6
14-15	2.9
16-17	0
18-19	5.7

Several survey respondents provided additional information about the level of responsibility they were undertaking (YC1, YC2, YC7, YC10, YC17, YC27). YC27 described their caring role for their brother as *“basically bringing him up outside school”*. YC17 revealed they provided a caring role to both their brother and mother, who had had a stroke. YC7 disclosed that they had *“a lot of responsibility as my mum’s primary carer.”* YC10 wrote of having to use their study time to ensure their caring role/tasks had been fulfilled. YC2’s comments illustrated the responsibility and essential nature of their caring role, when they wrote; *“I have other roles that need to be done to make sure that everything is running smoothly/calm”*. YC1 showed their levels of responsibility through outlining the different areas in their life that they were balancing;

“Not only was I attempting to work a job, go to school and study and care for my mother....”

5.2.4 Young carers' current educational status

Table 14 shows the current educational status of respondents. Of those respondents that were still at school or college, 25.7% were waiting to sit GCSE examinations and 37.1% were working towards As or A Levels (n=35).

Table 14: Current educational status of respondents (N= 35)

	Percentage of participants
At School	57.1
At a Regional College	14.3
At University	20.0
In Full Time Employment and Not in Education	2.9
Not in Education, Employment or Training (NEET)	5.7

A number of respondents volunteered further detail regarding their current education status. Of those young carers at university, they were studying a range of subjects including: Sociology with Criminology; Law; French and Spanish; Adult Nursing; and Engineering and Aerospace Engineering. Another was completing a Cache Level 3 extended diploma for Children's Care, Learning and Development (YC14). Overall, three respondents were pursuing careers in nursing, one in full time employment as a Staff Nurse and two were currently at university completing nursing degrees (YC25, YC28, YC32). For one of those identifying as NEET, it was due to re-location from England to NI rather than their caring role and they were actively seeking employment (YC27).

The highest qualification held by most respondents was at GCSE level, 28.6% (n=35) had obtained at least one of these. Table 15 provides a breakdown of the qualifications.

Table 15: Breakdown of qualifications held by respondents (N=35)

Qualification Level	Percentage of participants
Waiting on GCSE Results	20.0
GCSE	28.6
AS Level	8.6
A Level	17.1
BTEC	11.4
Diploma (NVQ's/VRQ's)	5.7
Bachelor's Degree	5.7
Other	2.9

Of those respondents who had received GCSE results (n=23), overall 39.1% achieved at least one A*Grade, 65.2% an A Grade, 95.7% a B Grade, 56.5% a C Grade, 21.7% a D Grade, 8.7% an E Grade, 4.3% a F Grade and 4.3% Unclassified. Overall, of those who had obtained AS Levels (n=11) 63.6% achieved a Grade A, 45.5% a Grade B, 27.3% a Grade C, 27.3% a Grade D and 9.0% a Grade E.

Of those who had achieved A-Levels, 18.2% (n=11) were awarded an A* Grade, 30.0% (n=10) an A Grade, 40.0% (n=10) a B Grade, 30.0% (n=10) a C Grade, and 10.0% (n=10) a D Grade.

5.2.3 The educational experiences of young carers

Overall, 65.5% (n=29) of respondents agreed or strongly agreed that they had a positive attitude towards their education compared to the 17.2% who disagreed or strongly disagreed that this was the case.

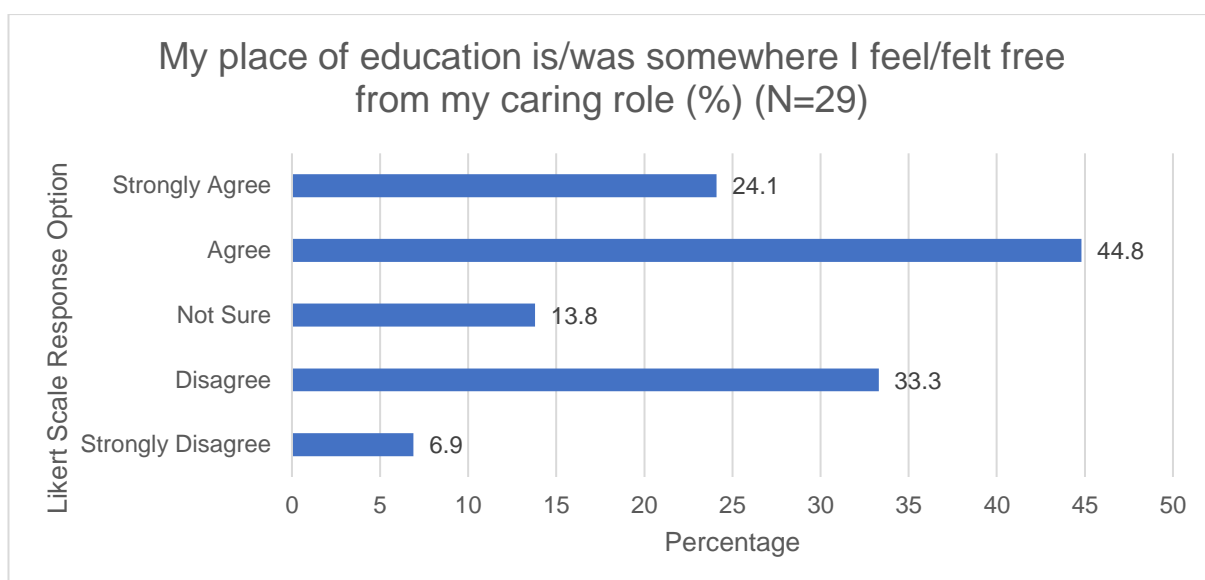


Figure 8: Responses to statement *My place of education is/was somewhere I feel/felt free from my caring role*

Almost 70% of respondents (n=29; 69.0%) agreed or strongly agreed that their place of education was somewhere that they felt free from their caring role compared to 17.2% who disagreed. Similarly, (n=29; 79.3% agreed or strongly agreed that their place of education was a break from their caring role, and 13.8% disagreed or strongly disagreed (Figure 8).

Over half of respondents (n=28; 60.7%) strongly disagreed or disagreed that their place of education was somewhere that added to their problems, although 21.4% agreed that they felt their place of education added to their problems. Over a third of participants (n=29; 34.5%) felt that their caring role *contributed to me feeling lonely at my place of education* and 51.7% did not. In relation to the statement about how their *caring role contributed to me feeling isolated at my place of education*, one quarter of respondents (n=29; 24.1%) agreed that they believed this to be the case but over half of respondents (62.1%) disagreed.

Regarding educators knowing about their caring role, an equal number of young carers (n=29; 37.9%), agreed and disagreed with this statement. Almost a quarter of respondents (24.1%) revealed that they were unsure if their educators knew about their caring role. For those participants, whose place of education was aware of their caring role, 56.5% (n=23) agreed or strongly agreed that this information was treated confidentially, while 39.1% specified they were not sure

if this was the case. One respondent strongly disagreed that their caring role was kept confidential by their place of education. Respondents were evenly divided about whether they wanted to inform their place of education about their caring role: 37.9% (n=29) strongly agreed or agreed, 37.9% strongly disagreed or disagreed and 24.1% were not sure.

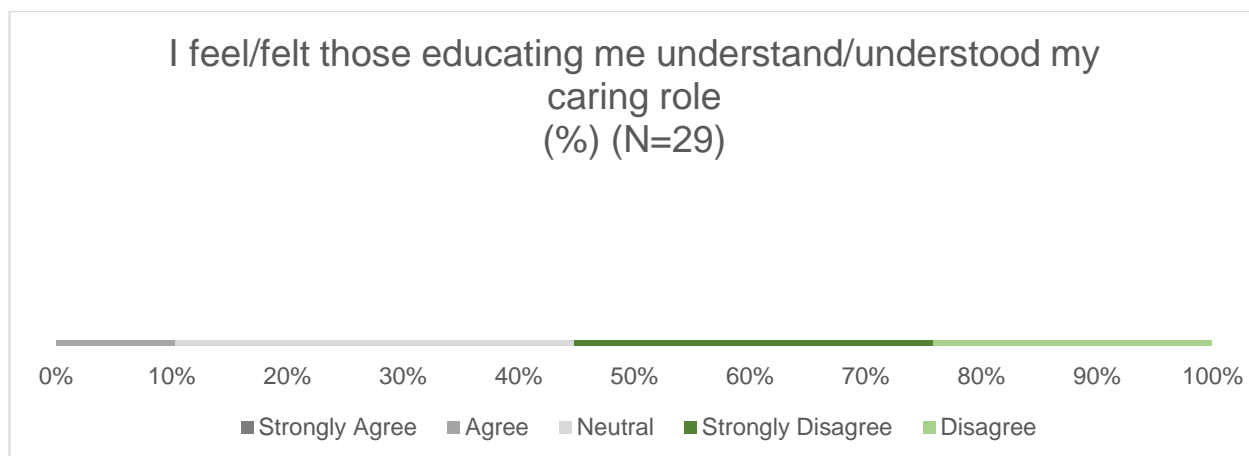


Figure 9: Responses to statement *I feel/felt those educating me understand/understood my caring role*

On the subject of whether those educating them understood their caring role, over a third (n=29; 34.5%) were unsure about this statement, but, over half (55.2%) strongly disagreed or disagreed that they did (Figure 9). YC14 elaborated on the lack of understanding they had experienced about the emotional impact of a caring role;

People don't understand what it's like for me to watch my dad being ill, in pain and needing help day in day out. People don't understand how upsetting it can be to be told by other people that 'it can't be that bad', 'I'm over exaggerating' or 'that I'm making it all up'. They don't understand how awful it is seeing your loved one being unresponsive and being told you've saved his life because of basic first aid knowledge. Sorry got a bit emotional writing that. (YC14).

Similarly, over sixty percent (n=29; 62.1%) strongly disagreed or disagreed that they felt supported by their educators. In contrast 10.3% agreed that they did feel supported and 27.6% were unsure. When asked if the support they did receive was the support they needed from their educators, 69.0% (n=29) strongly disagreed or disagreed and 20.7% agreed that they did receive the support they needed.

Three respondents gave further details of experiences with their educators. One young person had experienced *“a lack of compassion and empathy by educators”* (YC12). This was a thread that ran throughout other comments: one reported having teachers who knew of their caring responsibilities, yet *“they do not listen they tell me that I am late and I get marked late”* (YC17). Another reported making the conscious decision to tell only a *“few teachers about my role, as I feel few/little understand the magnitude of the situation”* (YC11).

The majority of respondents (n=29; 79.3%) agreed or strongly agreed that they were treated as an adult at home. In contrast, however, in response to the statement *I feel like I am/was treated like a child in my place of education*, almost a third (n=28; 32.1%) agreed or strongly agreed with this, just over a quarter (28.6%) disagreed or strongly disagreed and over a third (39.3%) of respondents were unsure. This was the largest number of respondents throughout Section 5 to select the *not sure* response option with both those aged 16 and 17, and those aged 18 and over reporting similar figures

5.2.6 Impact of caring role on grades

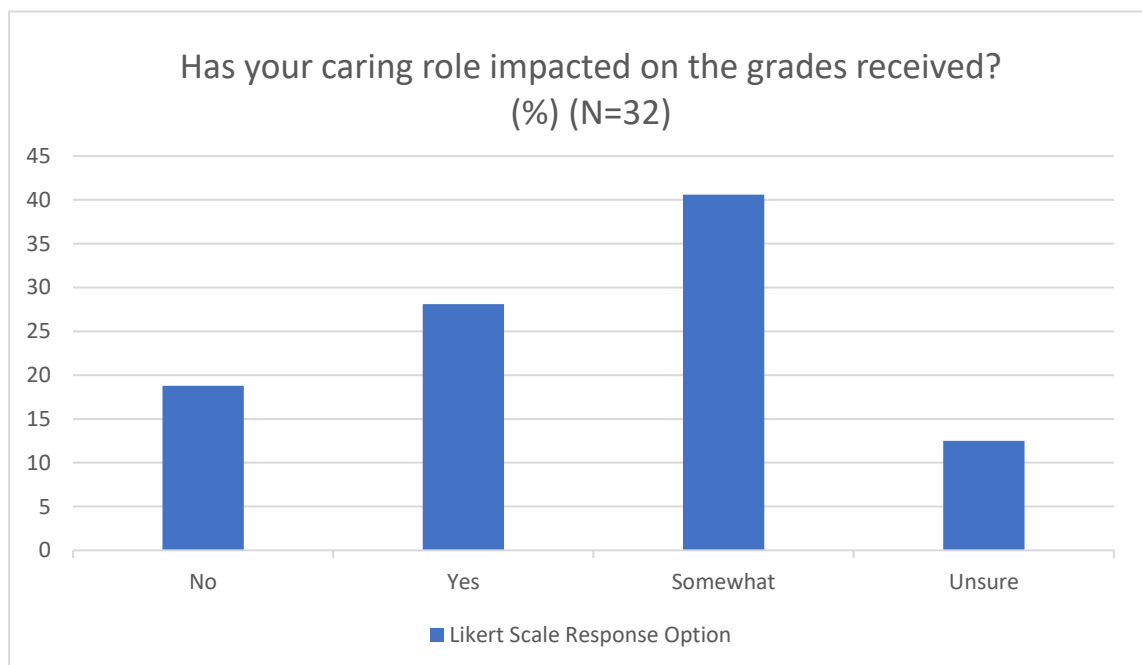


Figure 10: Response to question *Has your caring role impacted on the grades received?*

In response to a question about whether their caring role impacted on their education outcomes, 62.5% (n=32) respondents agreed or somewhat agreed that their caring role had impacted on their grades, 18.8% did not believe this was the case for them with 12.5% registered that they were unsure about this (Figure 10). Elaborating on the question *‘Do you feel that your caring role impacted on the grades?’*, seven respondents used this opportunity to admit they felt their grades suffered because of their caring role;

- *“I believe that my grades could have somewhat improved if I was able to create a schedule, however my caring role effected this”* (YC29).
- *“I feel like I could have achieved higher grades”* (YC28).
- *“Have to prioritise and sometimes grades...had to be put aside when family member needed care”* (YC25).
- *“I believe that my grades where hindered somewhat as I had to take time out of my studying to help/look after my mother”* (YC22).
- *“I have a lot of responsibility as my mum’s primary carer and with the amount of hours I care for her a week along with school may have impacted my grades”* (YC7).
- *“Bad grades at Xmas exams”* (YC4).
- *“Stress/worry may have hindered grades”* (YC31).

Respondents also provided explanations as to why they believed their grades had been impacted on, which can be illustrated in the following themes

Balancing their caring role with their education (YC17, YC20, YC25, YC27, YC28, YC29, YC33, YC35). For example, YC25 commented *“Not enough time to do everything. Only so many hours in the day. Have to prioritise and sometimes grades, homework’s etc had to be put aside when family member needed care”*.

- Study/revision time impacted by caring role (YC2, YC10, YC15, YC20, YC23, YC24, YC27, YC29).
 - Home environment not conducive to studying/revision (YC10, YC15, YC20, YC23, YC24).

- Respondents described how they struggled to get peace and quiet at home to study for example YC23 wrote; *“[w]hen I study it would be hard because my sister would come in and out where I was studying. Making a lot of noise etc”*.
 - Less time to study/revise because of caring role with their caring role taking priority (YC2, YC10, YC24, YC27, YC29).
 - For example, YC29 wrote; *“[A]t times I felt that it limited how often I could have been revising/preparing. I believe that my grades could have somewhat improved if I was able to create a schedule, however my caring role affected this”*. Similarly, YC2 commented *“[W]hen my people who are sick it means less time for schoolwork as I have other roles that need to be done to make sure that everything is running smoothly/calm”*.
- A change in cared for persons condition around exam time (YC1, YC14, YC17, YC31, YC32). Examples of some of the situations being faced around exam time by these young people:
 - Father having operations and having multiple collapses during their exam period (YC14).
 - Mother had a stroke and required extra care (YC17).
 - Sister developed psychosis during time of respondents A-level's (YC32).
 - While completing their degree, a young person's grandfather had a stroke and they provided during the night care to him (YC32).
 - Sister had surgery during respondents A-level exam period (YC32).
- Stress and or worry about their caring role (YC9, YC12, YC31, YC33).
 - Parallel to stressing about exams YC33 wrote that they were also stressed about their brother which impacted on both this young person's sleeping pattern and confidence (YC33).
 - YC31 whose cared for person had had surgery during their exam period openly commented that *“stress/worry may have hindered grades”* (YC31).

- More extreme was that in one case stress was cited by a young person as causing them non-epileptic seizures leading to several hospitalizations for them (YC12) They revealed *“At school I worried to the point I started to take seizures”* (YC12). This in turn led to them missing out on *“a lot of school”* (YC12).
- YC27 revealed that they had been worrying about their brother.
- YC9 wrote of not being able to complete homework as they were “distracted with worry” (YC9).
- Health of young carer (YC1, YC12, YC14). In these instances:
 - One young carer had two operations themselves and felt that it took them longer to recover as they still had to look after their father (YC14).
 - Stress caused non epileptic seizures for one young person which impacted on their school attendance (YC12).
 - Another, contracted meningitis which led to hospitalisation and them missing some exams (YC1).
- Absence from place of educations (YC9, YC22).
 - *“I believe that my grades where hindered somewhat as I had to take time out of my studying to help/look after my mother”* (YC22).
 - “Sometimes I couldn’t complete coursework as I had to miss school...” (YC9).
- Problems focusing/concentrating (YC14, YC28).

Compared to the answers selected by respondents in Section two, question seven, when asked in Section five to respond to the statement *I feel my grades/marks were impacted on by my caring role*, just under half (n=29; 48.3%) of respondents selected that they agreed/strongly agreed that their grades had been impacted on by their caring role with 34.5% disagreeing/strongly disagreeing that they felt this way.

5.2.7 Other impacts of caring role on education

In addition to asking young carers about the impact of their caring role upon their grades, they were also asked to respond to a range of statements to indicate the wider impact of their caring role on their education.

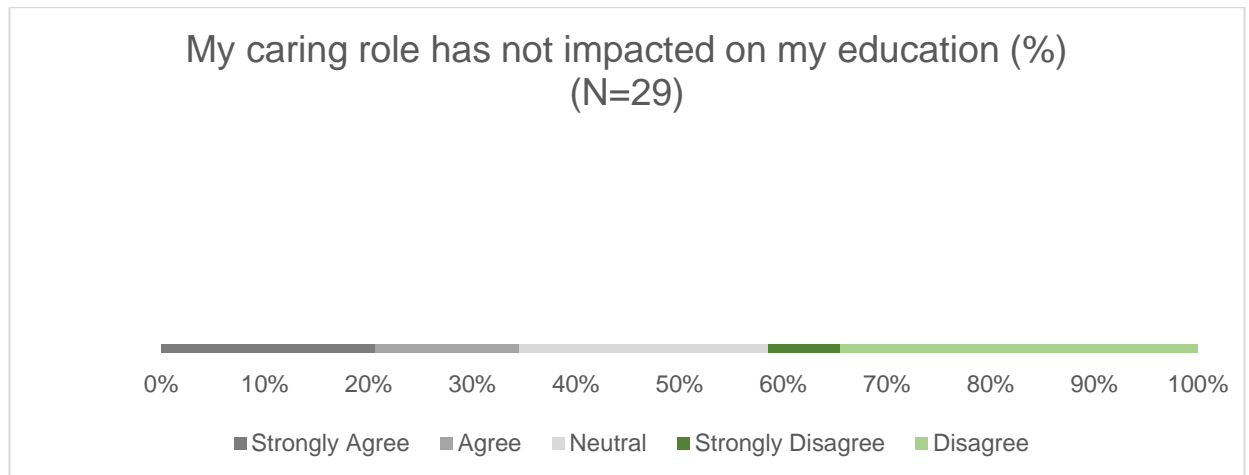


Figure 11: Response to statement *My caring role has not impacted on my education*

Over one third (n=29; 41.4%) of respondents disagreed or strongly disagreed with the statement *My caring role has not impacted on my education*, however 34.5% also agreed or strongly agreed that their caring role had not impacted on their education (Figure 11).

When asked to react to the statement *My caring role has had little impact on my education*, 55.2% (n=29) disagreed or strongly disagreed that this was the case and 31.0% agreed or strongly agreed that their caring role had little impact on their education. In response to the statement *My caring role has had a significant impact on my education*, just over a quarter (n=29; 27.6%) of respondents agreed that this was the situation they experienced. However, 51.7% disagreed or strongly disagreed that this was the case. When asked to respond to the statement *My caring role takes priority/took priority over my schoolwork/education*, there was little variance between those respondents who agreed/strongly agreed (n=28; 39.3%) and those who disagreed/strongly disagreed (42.9%).

The responses will now be outlined about the other possible ways having a caring role may impact on their education.

5.2.7.1 Non-attendance and lateness

Because of my caring role I have had to take time off from my place of education. Over half of participants (n=29; 58.6%), disagreed or strongly disagreed and 34.5% agreed or strongly agreed they had to take time off from their place of education. The response to the statement *I have been late to my place of education because of my caring role* saw a reverse response, with 55.17% (n=29) agreeing/strongly agreeing and 41.4% disagreeing/strongly disagreeing.

5.2.7.2 Concentration and tiredness

I have/had problems concentrating at school etc because I am/was thinking about the person I provide care to at home.

Over half of respondents (n=29; 58.6%) agreed/strongly agreed that they felt this way with almost a third (31.0%) disagreeing/strongly disagreeing. (YC25) described being distracted by their responsibilities even when at their place of education, for example having “*constant stress, worrying and annoyance being at education thinking about the people I care for*” (YC25). Another described how when their mother had been hospitalised, they found it “*increasingly more difficult to concentrate on school*”. Similarly, on the subject of tiredness, over half (n=29; 62.1%) agreed/strongly agreed that they felt tired at school because of their caring responsibilities, with almost a third (31.0%) disagreeing/strongly disagreeing this was the case.

5.2.7.3 Dropping out and NEET

I have considered dropping out of my education because of my caring role.

Almost three quarters (n=29; 72.4%) of respondents reported that this had not been the case for them, but 24.0% indicated that they had considered this. Two participants (n=35; 5.8%), identified themselves as NEET. Of the two participants one indicated that, this was not because of their caring role, no additional information was provided by the second participant.

5.2.7.4 Homework/ Coursework completion

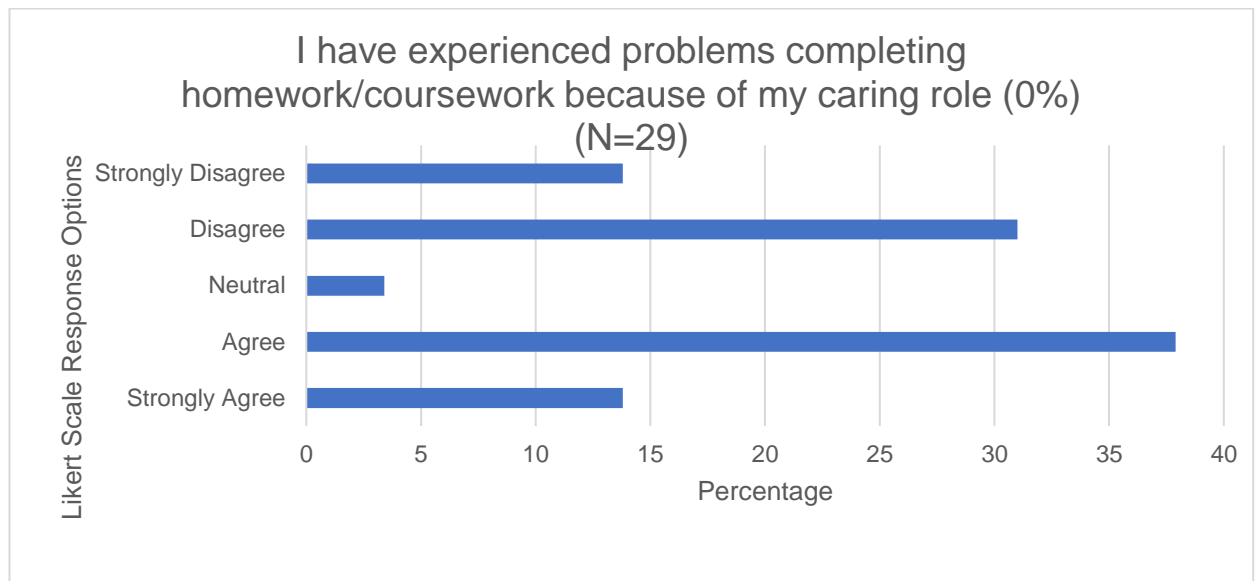


Figure 12: Response to the statement *I have experienced problems completing homework/coursework because of my caring role*

There was not a large variance between those agreeing that they had experienced problems completing homework/coursework because of their caring role ($n=29$; 51.7%), and those disagreeing that this was the case (37.9%) (Figure 12).

5.2.7.5 Financial

Two respondents ($n=28$; 7.1%) agreed that they had not been able to afford the required text books for their course compared with 85.7% who disagreed/strongly disagreed they had this experience. Just over ten percent ($n=29$; 10.3%) agreed that they could not afford to buy lunch at their place of education with 86.2% disagreeing.

Participants were asked whether (if applicable) their Education Maintenance Allowance (EMA) had been impacted by them having to take time off from their place of education because of their caring role ⁶⁹. Sixty per cent of respondents

⁶⁹ Education Maintenance Allowance is a payment of £30 made fortnightly to those aged 16 to 19 years old in school full-time or studying another course that is classed as eligible, attending all classes and living in a household with an income of £20,500 or less, or £22,500 or less depending on the number of dependent children. <https://www.nidirect.gov.uk/articles/education-maintenance-allowance-explained> consulted on 13/04/2020.

were not in receipt of EMA, but of those who were 57.1% (n=14) selected that their EMA had not been impacted on and 42.9% selected that it had. Of those whose EMA had been affected YC9 wrote they had *“missed some days, so I haven’t gotten it”*. YC12 indicated that they *“have had to take time off to look after my siblings or mother”* and YC27 admitted to missing school to collect their brother from school. YC14 wrote that *“if my dad was really ill it would take my mum and me to help him but also mum had to go look after my nana before she died so I was relied on to look after my dad”*. One respondent explained how even though they were absent *“due to my mum being so poorly”*, they told their FE college *“that I am poorly”* as they did not want to be seen to make excuses and as a result they did not receive their EMA (YC1).

5.2.7.6 Extra-curricular activities

In terms of extra-curricular activities, 51.7% (n=29) disagreed that their caring role stopped them participating, however 44.8% agreed this was their experience. Twenty percent of respondents agreed that their caring role impacted more on extra-curricular activities than on their homework, the same proportion agreed that it *impacted more on me spending time with my friends than on my homework whilst* 24.1% (n=29) did not agree that this was the case for them.

Just over 10% of respondents (n=29; 10.3%) agreed that they *could not afford to take part in extra-curricular activities*, whereas 82.8% disagreed that this was this was their experience.

5.2.7.7 Bullying

Just over seventy-five percent (n=28; 78.6%) reported that they had not experienced bullying at their place of education because of their caring role, however for 21.4% respondents, this was not the case. For 17.2% (n=29) of respondents bullying was associated with the stigma attached to the illness of the person they provided care to. Linking to this concept of stigma, over one third (n=29; 37.9%) agreed with the statement that *Some people in my place of education have a negative attitude towards the illness of the person I provide care to*, 51.7% did not. Illustrating this, one respondent commented on their

experience of a “constant negative attitude about autism by a lot of teenagers when I was studying” (YC25).

5.2.7.8 Future education decisions

Almost a third (n=34; 32.5%), responded that any decisions or choices they made about their future education had not been impacted by their caring role. This was compared to 47.1% who answered that it had either impacted or impacted somewhat on the decisions and choices they had made regarding future education choices.

In response to the statement, *My caring role has impacted on the choices I have made regarding further and higher education*, just over one third of participants (n=29; 37.9%) agreed or strongly agreed, with 48.3% disagreeing/strongly disagreeing.

Several respondents (40.0%) provided details as to how they believed their caring role had impacted on the decisions they had made about their future education.

Four respondents elaborated on how their caring role had an impact on their choice of university (YC9, YC11, YC24, YC26). For three of them, this was specifically linked to the location of their university choice (YC11, YC24, YC26). They had chosen universities close to home, YC26 described choosing a university “*closer to home to be able to come as and when needed quickly*” (YC26). Another young person (YC11) indicated they felt able to choose a university outside NI in Edinburgh because “*it is easy/handy to get home in case I am needed*”, they also disclosed that it was always their intention to leave NI (YC11). YC24 expressed how a NI university was their only option as they did not feel that they could leave NI because their family needed them (YC24). The fourth respondent revealed that their decision to attend university have to wait until they felt their dad could “*cope alone*” (YC9).

Five, respondents described their caring role as directly relating to their chosen career path. For example, YC14 told of how they would like to work with children but ultimately, they wanted to be a paramedic “*from seeing the paramedics work*

with my dad". YC32 explicitly said *"Having only known a caring role, I knew that it was what I wanted to work in"*. Similarly, YC25 wrote that *"Caring from a young age made me the person I am and I choose nursing as I am used to caring for family"*. YC33 explained that *"in a positive way I want to learn more about how the law can help individuals with disabilities and hopefully specialise in this area as a solicitor"*. YC35 wrote that originally, they had wanted to be a doctor but their sister's disabilities *"have made me want to work alongside other children with special needs"*.

In addition to explaining how their caring role had impacted on the decisions they made about their career path, one young person highlighted the importance of studying a *"good course"* as they believed this would enable them to *"get a well-paid job to assist my family financially when required to support us in our caring role"* (YC33).

Three young people revealed that they had left school or changed schools for three different reasons, each reason relating to their caring role. YC1 explained that they had left school and were now at a regional college which enabled them to care for their mother two additional days a week. They described this as *"part of the reason I left school"* as their new education option fitted better with their caring role. YC12 described having to change schools because of a lack of care and pastoral support, elaborating that their original school knew about their home situation but believing *"they did not want me because of it"* (YC12). The third young person revealed they had changed schools and repeated a year because in their own words; *"I did very badly in my GCSE's in June 16"* (YC15).

One young person, YC27, said they felt that the decisions and choices they made about their future education was impacted *somewhat* by their caring role. This young person said they wanted *"better understanding of caring roles and illnesses"* and also inferred they would have liked more guidance/help in relation to *"what opportunities there were out there for me"* (YC27). Another young person responded saying that they were unable to have a part time job at the moment, the inference because of the question being that this was because of their caring role (YC4).

When asked to respond to the statement *I feel my career prospects have been impacted by my caring role*, nearly a quarter (n=29; 24.1%) were not sure how to respond to this statement. Just under a third (n=29; 31.0%) agreed or strongly agreed with this statement, however 44.8% of disagreed or strongly disagreed that this was the case.

5.2.8 Support received

Respondents revealed that 60.0% had received support in relation to their education from other family members, 54.3% from young carers organisations, 42.9% from friends, 37.1% from their class teacher, 20.0% from a pastoral care teacher, 8.6% from a homework club, 5.7% from their school nurse or social worker and 2.9% from a neighbour (Figure 13). No respondent selected having received support from an Education Welfare Officer (EWO) and this question was left unanswered by two respondents⁷⁰. Respondents were invited to provide further details of any support they had received from other people/organisations outside of the options given, one respondent paid tribute to the support they had received from a counsellor from Lifeline.

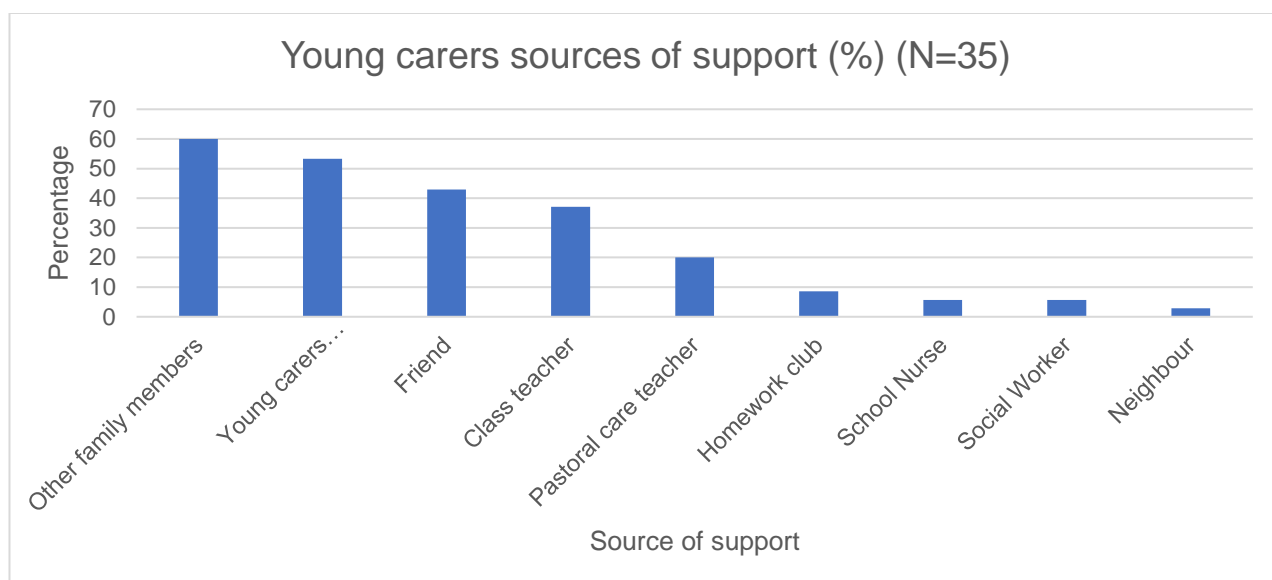


Figure 13: Young carers sources of support

⁷⁰ A school will make a referral to the Education Welfare Service should a pupil's attendance be a cause for concern. It is the role of the Education Welfare Officer (EWO) to contact the family and support the young person to improve their attendance.
<https://www.eani.org.uk/parents/education-welfare-service/about-the-education-welfare-service>
 consulted on 13/04/2020.

They type of support respondents received from being involved in a young carer's organisation, was categorised into eight different themes.

1. Advice (YC14, YC18, YC21, YC25, YC28). For example, they provided advice on issues such as how to balance education and a caring role, coping and revision skills.
2. A Break (YC9, YC10, YC11, YC12, YC13, YC14, YC20, YC24, YC25, YC31, YC35).

Respondents described the time they spent with their young carers organisation as a *“break away from caring and work”, “time out”, “time away to relax”, “gave me time to do things with no interruptions”* and *“took me out for a period of time where I could relax and ‘forget’ temporarily about my caring roles”*. As well as being a break, it gave young carers time to socialise (YC9, YC11, YC13, YC20, YC31).

3. The sharing of experiences with other young carers and seeing how they cope with their caring role and education (YC11, YC31).
4. Helped provide for basic needs of young carer and their family in light of financial difficulties (YC9). YC9 disclosed *“At one point they helped us get food when our money got stopped”*.
5. Project/Support Worker linking with young carers school, notifying them about their situation and organising support within school to allow young person leniency on certain things for example homework completion (YC7, YC22).
6. The example of leaders as influencers, one respondent commented that *“...leaders when I was younger used to influence study”* (YC25).
7. Providing general support (YC21, YC25, YC28, YC33).
8. The provision of/access to someone to talk to (YC20, YC33). One young person highlighted the importance of this to them when they wrote; *“[t]he one to one support I received was vital to me maintaining good mental health by being able to talk about my worries with someone outside my family who understood what I was going through”* (YC33).

Thirteen young people indicated a willingness to be interviewed via completed surveys.

5.3 Findings from interviews with young carers

5.3.1 Background

Six young female carers were interviewed for this research. Despite the committed efforts of the researcher and the staff in the young carers' organisations involved, no male young carers agreed to participate in an interview for this study.

Those interviewed ranged from sixteen years old to twenty-two years old. What follows is a brief profile of each young carer.

YCInt1- a 17-year-old female, an only child providing care to both parents since 2013. Living with her father but has daily contact with her mother. One has mental ill health and the other has physical illness. Waiting on AS Results, achieved 1A, 5B's, 4C's at GCSE.

YCInt2- a 16-year-old female, eldest child. Living with her parents and younger brother and sister. Provides care to her mother who has physical and mental ill health and brother diagnosed with Asperger's. Performing a caring role since the age of five. Waiting on GCSE results.

YCInt3- a 17-year-old female, youngest child, who lives with her parents and older brother. Provides care to her mother who has physical and mental ill health and brother diagnosed with ADHD and Autism. Performing a caring role for brother since age of four. Received AS results in August 2019, achieved 1A, 1C and 1D. GCSE results were 1B and 2C's.

YCInt4- 22-year-old female, eldest child. Lives with parents, has a younger brother who has severe autism and learning difficulties who is currently in residential care Monday to Friday. He lived at home until several years ago. Has completed her Bachelor's degree and is currently engaged in postgraduate professional training. Obtained 4A*'s, 4 A's, and 2 B's at GCSE, 4B's at AS Level and 4B's at A-Level.

YCInt5- 21-year-old female, youngest child. Lives with parents, other siblings have left home. Provides care to her father who is disabled and has several serious illnesses. Currently in employment. Achieved 10 GCSE's, 3 A's Levels and 2 A Levels. Went on to complete a Level 3 qualification at a Regional College.

YCInt6- 20-year-old female, eldest child. Provides care to mother, brother, grandmother and anticipating future care role towards father. Achieved 1 A Level, 3 BTec Level 3's, 1 AS Level, 2 BTec Level 2's and 8 GCSE's. Currently completing a nursing degree.

5.3.2 Experiences of education

Only one of the interview participants reported being happy with their experience of school (YCInt1). Two participants said they did not have a positive experience of education (YCInt4, YCInt6). YCInt4 cited the culture of the school she attended as a contributory factor, referring to the pressures of attending an all-girls school with its competitive, perfectionist environment, a lack of pastoral care and *"kinda a culture inside school that you had to just, you know, get on with it, get your grades and then go off...no one person who understood"* (YCInt4). One interviewee described their education experience as stressful, outlining how much they cared about their education, their own personal need to be perfect at school and having high expectations of themselves to achieve and be top of the class (YCInt2). Another participant described having *"a bit of a mixed experience"* (YCInt5), revealing *"...between teachers not always being supportive, things going on at home and then being bullied-there was a lot going on"* (YCInt5).

Overall young carers had a mixed experience of support in school. Three interviewees explicitly said that they did not feel supported in their place of education (YCInt2, YCInt4, YCInt6) with one saying it was not until their 14th year of education that they felt supported" (YCInt6). Only one participant (YCInt3) said they received the support that they needed and another (YCInt5) reported a mixed experience of support- sometimes good other times not.

For the young carers who had a negative experience they attributed this: to an education system that they deemed uncaring and a *"disaster"* (YCInt6);schools

having other priorities to pastoral care despite what they said “...*they preach so much and this whole pastoral care in school, like they preach it and I never received any*” (YCInt6) and a belief all their school cared about was good grades (YCInt2). One interviewee felt their school only provided support if a pupil was on a “*particular pathway*”, for example going through UCAS with it being “*frowned upon*” if they were completing a Level 5 qualification or a BTEC (YCInt6).

YCInt4 said when they were at school, no advice was given as to who to go to if they were having a pastoral problem, and they “*didn’t know the option was there*” (YCInt4). In relation to their schoolwork, this same young carer commented that should they have a problem, they had to make an appointment to see the relevant teacher and even then, they were of the opinion that “*probably wouldn’t get it anyway*” (YCInt4).

5.3.2.1 Young carers experience of university

Two participants combined their caring role with completing university courses (YCInt4 and YCInt6). They had contrasting views about the support they had received. YCInt4 described their university experience as being “*the first time I experienced someone saying ‘I understand this is difficult for you- do not worry’*”. YCInt6, in contrast believed they received more help/support at school than at university. Although they did speak of positive support from a tutor, they commented that being at university “*made things worse*” due to the structure of their nursing degree which consisted of classes for six weeks and placement for six weeks when shift patterns varied. As shift patterns for placement were not necessarily known in advance of the placement starting, it made planning in advance for relative’s hospital appointments difficult.

5.3.3 Attitudes towards education

Five out of six interviewees agreed that their education was important to them (YCInt1, YCInt2, YCInt3, YCInt5, YCInt6) and that they wanted to do well. YCInt2 described herself as “*a very ambitious person, very driven person*”, YCInt3 said

that because of the importance they placed on education they always tried their best. YCInt6 commented that *“...my education was important. I cared about my education and I think wouldn’t have had as good an attendance if I didn’t start off with 100%”*, the value they placed on education motivated them. As well as recognising that the importance of doing well with her education for the future, YCInt1 also commented that she enjoyed her education because she enjoyed the subjects she was studying.

YC4 described their attitude towards their education and school as being mixed- *“kinda on and off, sometimes I was committed to it and sometimes I wasn’t”* (YCInt4). She spoke of not knowing how hard she needed to work until she received grades she was not happy with and she learned from that experience. She admitted to enjoying the social side of sixth year more than studying as socialising was an escape in a situation where she felt *“school wasn’t really supporting me in that sense so I felt the only way to try and get that escape was going out with my friends and pretending that doesn’t exist”* (YCInt4).

5.3.3.1 Caring as priority

Four of the interviewees communicated that their caring role took priority over their education (YCInt2, YCInt4, YCInt5, YCInt6). YCInt2 described completing their caring tasks first which meant having to stay up until 2am to complete their revision. YC5 explained that their attitude was *“my homework will be there in half an hour”* and that they were unlikely to be able to concentrate on their work if they did not fulfil elements of their caring role first (YCInt5). YC6 explicitly said *“...caring is always the priority, something happens in work, I will drop work, I don’t care, sack me, whatever”* (YCInt6).

Two participants outlined other consequences in prioritising their caring role (YCInt4, YCInt6). YCInt4 described not getting enough sleep, not functioning as well as she usually would at school and feeling frustrated that she did not receive any consolation for that. YCInt6 described a situation of being in A&E with a person she cared for and having to be absent from her nursing placement. Although the hospital was understanding she still needed to make up that 12-hour shift which added to her pressure. This same young person also expressed

she was *“quite lucky that I am smart”* but she felt *“I would be so much smarter if I had time”*. Instead, she described her life as *“just a constant panic”* because she is *“too busy chasing and running after people making sure stuff is done”*, leaving her having to do *“a nine months assignment in a week/three days”* (YCInt6).

5.3.3.2 Balancing education and caring

Three interviewees reported that their caring role and their education conflicted (YCInt2, YCInt4, YCInt6). YCInt2 described it as *“this is something that I have to do and my caring role obviously conflicts with that a lot because it’s like do I revise-do I help?”* She elaborated, *“...whenever I am at home I am worrying about school and whenever I am at school I am worrying about home”* (YCInt2). YCInt6 described the relationship as; *“they just bounce off each other, they are the opposite”*. YCInt6 provided an insight into balancing their education and caring role. She described how *“There’s only one of me- there’s four of them”* and illustrated how her life consists of *“going to uni, coming home, taking someone to a hospital appointment, making sure the doctors were phoned and all that there and then getting time to myself”*. YCInt6 also described an occasion where she had submitted an assignment from A&E after a seven hour wait with a relative.

5.3.3.3 Does not let caring role interfere

YCInt1 did not see any relationship between her caring role and education because in her opinion it was her *“normal to deal with...a part of everyday life”* (YCInt1). Another interviewee said she tried not to let her caring role interfere with her education (YCInt3). Passing their driving test had helped improve this young person’s school attendance as she was no longer having to rely on her mother to drive her (who she provided care to). Prior to this should her mother have been having a bad day and not be able to take her to school she would not have attended.

5.3.3.4 The importance of a positive mindset

Three interviewees attributed coping with the joint demands of caring and education with having a particular mindset (YCInt1, YCInt5, YCInt6). YC1 explained she had the attitude to *“just sorta take it as it comes”*. For YCInt5, their mindset towards their education was dependent on how home life and the cared for person was at that time; if her father was particularly ill her attitude would have been *“no, I don’t know, haven’t a clue”* whereas if he was well her attitude would have transformed to *“yes, I got this, I can do this”*. In addition, the level of support she was receiving also contributed to her mindset. YCInt5 also acknowledged that it was important to her to prove people wrong but to show her dad *“that I’m not letting things get me down”* (YCInt5). YCInt6 described themselves as being *“so- strong headed”*, something all her family and friends recognised, and believed it was this mindset that gave her the motivation to *“push myself through it”* (YCInt6). Education was also seen as a distraction for YCInt6, providing somewhere *“to like turn your head, you know like a distraction”* (YCInt6) and that they had *“this thing like I just had to be in school”*.

5.3.3.5 Educators informed about caring role

Three interviewees confirmed their place of education was aware of their caring role (YCInt3, YCInt4, YCInt5). Another said that specific teachers knew about her circumstances, but school had not been informed (YCInt2) whilst two indicated that their place of education had not been informed (YCInt1, YCInt6). Those young people who indicated their place of education had not been informed offered several explanations for this (YCInt1, YCInt2, YCInt6). YCInt2 said that this was their decision as they wanted to keep their caring role and education *“as separate as possible”*. Those teachers who were aware of their situation learned about it because their work had been impacted and their young carers worker had made contact with them. YCInt1, did not inform their school because they said, *“I don’t really see it like as a big deal”* (YCInt1). YCInt6 said that the reason they did not inform their place of education was because *“it’s easier.... Because no one is going to be able to stop it”*, they also believed that no one cared (YCInt6).

5.3.4 Young carers and teachers

5.3.4.1 Young carers experiencing supportive teachers

Four interviewees outlined the importance of the support they had received from one or two particular teachers at school (YCInt3, YCInt4, YCInt5, YCInt6). YCInt3 described her experience of a supportive vice principal, who helped her reintegrate back into school after a period of absence. YCInt4 spoke of “*a couple of teachers in my school... they were brilliant*”, who if she had a problem with her work she could talk to, although emphasised that it was only “*one or two come to mind and that’s out of a lot*” (YCInt4). YCInt5 commented that her school Principal and her pastoral care teacher were supportive. She outlined how the Principal had helped when there were queries about her non-attendance at extracurricular meetings and how the pastoral care teacher allowed her to use their office to work if she needed space to concentrate. She also acknowledged other teachers empathising with her situation and of being able to talk to them about their experience of providing care to a relative. YCInt6 described how “*one teacher made all the difference*” for her when she was completing her A-levels, accrediting the understanding and support received from their Health and Social Care teacher as being the reason they received 2A*’s in that subject. She commented that she was happy in these classes, and “*wasn’t as stressed as I needed to be*” because of her relationship with this teacher and their sensitivity to her situation;

She knew by your mood, she knew by your engagement in class. If you were having a good day (inaudible) if you were stressed. You know she would pick up and you could cry to her... (YCInt6).

5.3.4.2 Lack of understanding from teachers

Two of the young people interviewed outlined situations when they had experienced a lack of understanding from teachers (YCInt5, YCInt6).

Some of the teachers couldn't understand if I didn't have the right forms, like there was days I forgot my blazer and that was like the main thing of your uniform and they were like 'how could you be so stupid and forget that?', and you're like, if only you knew, if only you knew! (YCInt5)

YCInt5 commented times “*where teachers were useless and didn't really care what was going on at home*”. She described her experiences with a particular teacher who she felt did not care about her home situation and who they felt was hostile and unhelpful. YCInt5 said she was unsure whether this teacher was unsupportive or just did not like her. With other teachers YCInt5 felt that when informed about her caring role it was as though;

it was a passing comment and [they] weren't really actually listening never mind really knowing how the impact of what's going on at home can really impact my work and they were shouting at me because I either forgot books or forgot to do homework's or didn't do a homework right (YCInt5).

(See also section on Problems talking to teachers about their caring role which outlines the difficulties one young person experienced because they did not feel able to speak to a teacher about their caring role/home situation).

YCInt6 recalled an experience with the school head of sixth form, who when approached with a request to drop an A-level subject, told them: “*you are too far into it now-just keep going*”. (YCInt6) YCInt6 failed the A-level she had asked to drop and described the encounter as having “*no empathy [or] compassion for anyone*” (YCInt6).

5.3.4.3 Teachers not responding as the young person wanted

One young carer revealed several experiences when teachers were aware of their caring situation but acted in ways that were not sensitive (YCInt5). Examples included teachers announcing in front of their class “*oh you've got to go to your counselling now*” and their experience with an examiner during a GCSE exam when her dad had been taken ill. What YCInt5 said about this has been included verbatim in its' entirety to convey the impact this situation had on the young person:

I was really in the zone, I remember thinking I've actually really got this, I'm doing well, and then I watched the receptionist of the school coming in and talking to the examiner and I was like 'hmm, that's strange, normally they're not allowed to interrupt exams'. So then this examiner walked up and down past me about six times and where I was the floor was really creaky in the gym and I was like, why are you being so weird, normally you just walk up and down and away you go, or you keep walking up and down obviously to make sure people aren't cheating or whatever, but I was like 'why do you keep hovering at me', I could feel her looking down over me but it was actually, she was looking at the card on my table which had my name, so she was looking for me and I was like, 'why? Why are you doing this? I'm not cheating, I'm genuinely doing the exam' and your mind was in overdrive. She ended up actually tapping me on the shoulder and goes 'how are you finding the exam?' and I was like, 'this is weird, ok it's a bit hard but I'm kind of doing ok'. So, I continued to write and she was like 'how far along are you?', I was like 'I'm about half way' and continued again. I remember being like 'what are you doing, is this a distraction tactic or something of making me fail or what is going on here?!' so I remember trying to listen to her but also write, so I've dyslexia, so I know I don't have much time and every minute is precious. I don't like being rude and I need to be rude to get the exam done but she was like 'ok so when you finish your exam and the papers are being collected can you get yourself into reception?' and I was like 'what?!' This was forty-five minutes into the exam and I hopefully had about another forty-five minutes, and I was like 'um ok why?' And she said 'oh just go, it'll be fine' and I'm like 'what, why?!' and I'm freaking out and then I couldn't concentrate and I kept looking round me and people are just like constantly writing and I was like, I can't even remember what I was thinking about, I can't even remember what I was doing, I can't remember my answer, I can't remember what the question was asking me to do?! So, I kind of went into overdrive, so I tried to finish it but I knew I struggled the rest of it, I couldn't concentrate (YCInt5).

5.3.4.4 Problems talking to teachers about their caring role

Four interview participants (YCInt2, YCInt4, YCInt5, YCInt6) disclosed that they either worried about their teacher's reaction to being told about their caring role or that they struggled to tell their teachers about this.

One young person was genuinely worried that her place of education would not take her seriously if she disclosed her caring role and was scared that she was not allowed to ask for help. When asked why she felt this way she responded, *"Because I am always the one who is there to help other people"* revealing that her perception was based more on personal feelings than on previous bad experience (YCInt2). Similarly, another young carer was concerned that her teachers would consider her caring role a *"good enough excuse"* for not completing homework tasks (YCInt4). YCInt4 also worried about her peers overhearing disclosure of her caring role to teachers because she felt then she would be *"seen as a certain way"* and people would be judging her (YCInt4).

YCInt5 explained that there were times when they felt *"so vulnerable and so emotionally low"* that they would be unable to open up about their caring role because they were not sure how the person with would react- in particular, they did not want someone's pity (YCInt5). YCInt5 described choosing to go to a teacher who they trusted and who knew about their caring role to help them deal with a situation with another staff member whose reaction they were worried about. This resulted in them experiencing friction with the teacher they had chosen not to approach directly.

YCInt5 also commented that there were times when she felt as though she was bothering her teachers (YCInt5). Bothering them in the sense that she felt like *"I was the one having to constantly go back"* and update them about the situation at home. She said;

Like I think at times I just felt like I was annoying them or they were kind of like 'oh I have too much to do' and it kind of felt like they didn't care about how you felt which obviously isn't what you want or want to hear, I think maybe that's another thing towards teachers.

What they said would have made this situation easier for them was if teachers made the approach to them or followed up on previous conversations as in addition it would have meant they *“genuinely care[d]”* (YCInt5).

YCInt6 was of the opinion that if she revealed the reasons why she was unable to complete work her tutors would ask her *“how many times are you going to use that excuse”* or threaten her with deferment which she did not want to happen because in her words *“it’s only going to get frigging worse”* (YCInt6).

5.3.5 The impact of caring role on education

5.3.5.1 Impact on grades

Three interviewees felt that their grades had been affected by their caring role (YCInt2, YCInt5, YCInt6). YCInt6 disclosed that they were having to repeat an exam at university they had previously failed and that they had also failed an A level subject they had previously asked to drop because they were feeling under pressure (See section on Lack of understanding from teachers). YCInt2 commented that *“my exams would, like my grades would be impacted by the fact I am having to prioritise my work sometimes, showing up late to classes sometimes. Having to go home early so missing stuff”*. YCInt5 explained that her father went into hospital during her GCSE exam period and that she *“couldn’t really cope with some of the revision, so then when it came to sitting the rest of my GCSE’s I wasn’t in the zone”*. Similarly, her father was taken to hospital the night before one of her ‘AS’ exams. She communicated that; *“I still think that I could have probably done better in other exams and stuff because they were all around the same time and as I said, I did pass all of them, a few I had to resit and remark but I got there in the end. 100%, it definitely did affect my grades and stuff”* (YCInt5).

5.3.5.2 Impact of caring role and decisions made about their future

Three interviewees indicated that their caring role had directly influenced their choice of career (YCInt2, YCInt3, YCInt6). One wanted to become a

paediatrician, one a nurse and the other wanted to go into psychology because they had grown up around mental ill health. Regarding the career choice they made, YCInt6 explained that;

[Y]ou know if you are brought up caring for someone or if you are compassionate, if you are used to pressure, prioritising, emergency situations, you know where you are going (YCInt6).

One participant revealed she was keen to take a gap year but was unable to because of a joint commitment to both parents who had separated (YCInt1).

Three of the interviewees also revealed making choices about their future based on proximity to their cared for person (YCInt2, YCInt4, YCInt5). YCInt5 spoke of choosing a job close to home so she could easily get to the person she provided care to and YCInt2 spoke of wanting to move across the water for university but staying on the west coast of the UK so they can get home quickly if necessary. One interviewee was eager to complete their education as they believed this would liberate them from the pressure of homework which added to their caring responsibilities.

Get it done. That's why I don't have a positive impact on education because I am just over it. I just want it to be done because I know that once I am out of education, that weight is off my shoulders. I don't need to worry about homework, I can come home from work and go right everyone let's get dinner, not I have to do homework, I have to do tutorial prep, I have to do dinner, I have to do washing, I have to do this I have to do that, I have to do this, you know. (YCInt6)

5.3.5.3 Attendance

Five out of the six interviewees recalled some level of impact on their attendance because of their caring role (YCInt1, YCInt2, YCInt3, YCInt4, YCInt5). One had missed school just once (YCInt1), others more frequently (YCInt3, YCInt4, YCInt5), whilst another (YCInt2) said they missed classes but “*never a whole day*”. Whilst interviewees identified their caring role as a reason for absence, YCInt4 revealed that she missed some days due to “*lack of sleep or being*

exhausted or em, yeah say we had a difficult time, you know and I want to be at home with my parents" (YCIInt4).

YCIInt6 who said their attendance was not affected by their caring role, revealed that they did not miss a day in secondary school and received a trophy for attendance. This young person, who provided care to four relatives, commented that *"For what I had going on at home my attendance was so good"*. They described how they would have been sent to school after having dealt with their mother's seizures at home but that they themselves preferred this because they *"had this thing like I just had to be in school"* as this was where their support group- their friends where (YCIInt6).

5.3.5.4 Bullying

Three interviewees recalled experiencing bullying at school that was linked to their caring role (YCIInt2, YCIInt4, YCIInt5), two had not experienced bullying (YCIInt1, YCIInt3) and one had experienced *"very, very, very little"* (YCIInt6).

YCIInt2 described being bullied partly because of the responsibility she had for her younger brother but also because people felt she was *"too mature...acting like a mum"*. YCIInt4 did not classify her experience of rumour spreading as bullying but it could be defined as such. She recalled hearing others saying *"it's not fair that she gets extra time just because her brother has autism.... people really saw that as a negative if they saw someone as benefitting from something going on at home"*. Both YCIInt2 and YCIInt4 associated their experiences with the immaturity of their peers. YCIInt5 related the bullying they experienced to her options being limited due to her parents being unable to work and she felt this was exacerbated by attendance at an all-girls school (YCIInt5).

5.3.5.5 Relationships with peers

One young person said they had *"kind of closed off my friendships"* because they either did not want to leave the person they cared for or were needed at home (YCIInt5). YCIInt5 disclosed that peers fallen out with her because she did not want them to know certain things about her caring role. They also outlined the lack of

understanding they had received from their peers when they had become upset at school because of what they were experiencing at home;

...there was certain people who would be like, 'why are you crying, why are you getting on like a baby?', the amount of times I was called a baby for crying or taking myself off to the bathroom and they would have heard me crying in the bathroom or like leaving school and then there would be a million questions of like 'oh why did you get to leave school, you got it easy', and I'm like, 'hmm if only you really knew'(YCInt5).

One interviewee conveyed her caring role was something that they struggled to talk about to their friends, describing it as something personal to them *"A lot of my friends, actually still to this day don't really know. A lot of my really close ones would but some just don't"* (YCInt4).

5.3.5.6 Stigma

Half of interviewees felt a stigma was attached to their caring role by their peers (YCInt2, YCInt4, YCInt5), with one of these believing this extended to their teachers as well (YCInt5). Illustrating what they meant by stigma, YCInt2 said *"people think being a carer means this so she must be like that"*. For YCInt4, stigma was something that set them apart from their peers, particularly in a school environment that promoted perfectionism and competitiveness which could lead them to being judged. They outlined not wanting to share their caring role as she *"wanted to fit in with everybody and that is something and although it's not very common, that's something that sets you apart from everyone else in a big way"* (YCInt4).

5.3.5.7 Tiredness and concentration problems

Half of interviewees reported experiencing tiredness at school because of their caring role (YCInt2, YCInt4, YCInt5). YCInt2 disclosed that *"a couple of times I have asked to get out of class to go down to the nurse's office to lie down"* because they felt so tired it was impacting on their concentration. Similarly, YCInt5 described tiredness as affecting her concentration resulting in being

shouted at by a teacher. YCInt5 also provided an insight into how/why her caring role left her feeling so tired, she revealed:

...you're up and down during the night, like if you heard him fall you were bouncing up out of the bed and it would take you a while to get back over to sleep. It just really depends but it's just really the same now, you're always listening out and even when he's in hospital you think you hear him but you're like oh no it's ok, he's not actually here.... you still are listening out or you're like what should I be doing, and then because I'm not with him, I should be doing something but there's nothing to do because I'm not with him (YCInt5).

Four interviewees described problems with their concentration because of their caring role (YCInt2, YCInt4, YCInt5, YCInt6) and half of interviewees associated their concentration issues with worry about their cared for person while they were at school (YCInt1, YCInt4, YCInt5). YCInt2 commented how this affected them; *"It's a case of someone will say something and it will just go over my head and I won't remember whatever has been said to me"*. YCInt6 outlined how their concentration was affected at school after an emergency at home; *"when you are going into school after something like that you are panicking, you are distracted yourself you can't focus. Like there's no point me being in class if I know I'm not going to retain anything"*. Two interviewees described their concentration problems as tiredness related because of being up at night to provide their caring role (YCInt4, YCInt5).

5.3.5.8 Lateness

Four interviewees reported some level of frequency of being late for school because of their caring role (YCInt2, YCInt3, YCInt4, YCInt5).

YCInt3 and YCInt4 stated they were late all the time because of issues associated with their sibling's condition making it difficult to leave the house in the morning. YCInt5 said they were sometimes late as their cared for person was perhaps experiencing symptoms that made them unable to drive. YCInt2 recounted that

they wouldn't be late very often, it was when something significant had happened at home with their cared for person.

5.3.5.9 Homework or coursework completion

Half of interviewees expressed that they had experienced problems with homework completion (YCIInt2, YCIInt4, YCIInt6). YCIInt2 admitted to sometimes managing to complete homework *"in the ten minutes you have in class before the teacher says anything"*; other times she would apologise and say she had forgotten it, in more extreme instances she would ask her support worker from a young carers organisation to contact the teacher on her behalf. YCIInt4 described her problem with completing homework was sometimes that she *"didn't get them done as well as I could"* (YCIInt4). YCIInt6 explained how she had tutorial preparation to complete for her university course three days a week and this was something that had to be completed, which put her under pressure:

"you need to have that done. You can't go into that class and sit in class like a headless chicken... they will look at you and go 'where is your work?'"

YCIInt6 had a lot to say on the area of completing homework and coursework completion, they felt the quantity of homework given, which they claimed could take up to four hours, was too much to balance on top of their caring role and disclosed when she was at school she would've gone *"days without showers...days without properly eating"* in order to fit everything she needed to do into her day(YCIInt6). They also felt that teachers could be more flexible regarding coursework deadlines and if need be help pupils apply for exceptional circumstances.

5.3.5.10 Dropping out

Dropping out of their education because of their caring role had been considered to some extent by two participants (YCIInt4, YCIInt6). YCIInt4 described it as a

“fleeting thought” at times when *“this is difficult and I just kinda can’t put in the hours to it”*. She disclosed that ultimately, they had known from a very young age that they wanted to study law and were very motivated to do so, just at times they would’ve have questioned whether they *“should be aiming that high or...should I go easier on myself”* (YCInt4). YCInt6 admitted to having considered this or deferring their course for a year as but this was not really a viable option for them. In one sense they thought doing so would have its benefits and they *“would happily go back a year, it would probably take a lot of stress off me, I would be financially able to get myself on my feet. Get myself round. Could probably focus on my mental health a bit more”*. The reality, however was they were aware that due to the condition of the cared person, the caring situation could become much more intense, and that; *“It’s only going to get worse, you know if you can manage, if you can sort of stressfully get through”*.

5.3.5.11 Extra-curricular activities

Three interviewees described enjoying extra-curricular activities however they did experience difficulties attending due to their caring role (YCInt2, YCInt5, YCInt6). Each of these interviewees related all or part of their difficulties to transport problems. YCInt2 explained attendance problems were because *“a lot of the time they are after school or at times when mummy cannot drive because of her medication. Her medication at the moment, affects when she can and can’t drive and my house is a 40minute walk from school, on the days whenever it is too late to walk home, there’s nothing else I can do”*. YCInt5 experienced similar problems if her father for example had a hospital appointment or was at day centre, so her attendance *“depended on the situation on the day”* (YCInt5). Other times she would miss out because they had to go home and help after school. She was told that she was *“going to be kicked out of these clubs”* because she couldn’t attend every week, but her Principal spoke to the relevant teacher/teachers for her to stop this happening. YCInt6 described the importance of extra-curricular participation: *“I love sport. I took part in after school activities, sporting stuff. Because, if you put your headphones in and run around track, you’re not focusing on anything else...that’s your down time. Sport was my down time”* (YCInt6). For

those young carers who said their extra-curricular activities were not impacted by their caring role (YCInt1, YCInt3, YCInt4), two stated they *“could not be bothered”* or they did not enjoy attending such things as they did not like being out of their comfort zone (YCInt3, YCInt4).

5.3.6 Sources of support

This section will outline the types of support and sources of support interviewees received to help them with and or in their place of education.

One interviewee commented that whether they felt supported impacted on the mindset they had regarding their approach towards education. They illustrated this by stating;

“...I know on the times where I had less support I was like ‘no, I don’t want to do it, don’t care’ but if I had a lot of support I’d be like ‘right this is exactly what I want to do’ (YCInt5).

5.3.6.1 Support from family

Half of interviewees referred to the role their family played in helping them manage the relationship between their caring role and their education (YCInt3, YCInt4, YCInt5). YCInt3 described her mum as always having pushed her to do homework because *“she always valued that on top of everything else”*. She did however disclose that at times she felt that her brother’s (who she provided care to) education *“was always the main focus”*. YCInt4 expressed that her parents were supportive, wanted her to succeed and enabled her to focus on her studies when she needed to. For YCInt5, her father, whom she provides care to, reminded her that she had homework to do when he witnessed her putting his care needs before completing her homework (YCInt5).

5.3.6.2 Support from peers at school

Three interviewees discussed the support they received from their peers at school. One, favoured turning to their peers instead of teachers, saying they would “*probably*” approach a pastoral care teacher should their friends be unable to help them (YCInt1). YCInt6 spoke of her friends as her “*backbone*” and of how regardless to what was happening at home she did not want to stay home from school because that is where her support network, her friends where.

5.3.6.3 Support from teachers/education support staff

The support that four interviewees described receiving from teachers has already been outlined in section 5.2.5.1 ‘Young carers experience of supportive teachers’, when the positive impact was highlighted of young carers experiencing one or two particular teachers at school. In addition to support received from a teacher, an interviewee spoke of the benefit of access to a quiet place provided by the school Special Educational Needs Co-ordinator (SENCO). They explained:

...the SENCO had this store across from her room and she knew that I needed a place to be by myself and concentrate on my work or concentrate on what it was I needed to do, whether that was to cry, or whether that was to actually get work done without distractions around me....it sounds horrible but I was actually very thankful for it (YCInt5).

5.3.6.4 Support from a young carer’s project/worker

Five out of six participants mentioned the role a young carers organisation generally and individual young carer workers played in supporting them with their education (YCInt1, YCInt2, YCInt3, YCInt4, YCInt5). One young person described their support worker as “*the main support I would have*”, they were someone they could talk to and help them when they were feeling frustrated about their mother’s condition (YCInt1). Another described their young carer worker as their “*main support throughout secondary school*”, this regular support gave her “*someone to vent to*” (YCInt4). In two cases, young carers workers were involved

in direct contact with the school (YCInt2, YCInt3). For one, this was to help them reintegrate back into school after a period of non-caring related absence, and for the other it was to inform the school that her work had been impacted by their caring role. YCInt5 accredited social activities with peers organised by a young carers organisation as providing them the opportunity to go out with people *“who did know what I was going through but knew how to deal with it”* (YCInt5). She described the importance of the relationships she had there in helping her with the ups and downs of her caring role during her father’s illness.

5.3.6.5 Support from school nurse

One young person described going to the school nurse’s office to lie down when they are having problems concentrated because they felt exhausted. This same young carer was hesitant about their school knowing about their caring role but when asked if they felt supported at school, they immediately mentioned their school nurse and said *“if she knows I’m really not doing do well she will call mummy to come and pick me up but only if mummy can- depends”* (YCInt2).

5.3.6.6 Counselling

One interviewee was provided counselling within their school to help them cope with their circumstances. Unfortunately, they described how there was a lack of continuity in relation to the counsellor they saw which made them feel;

...you’ve already told one person and you’re like I’ve told you that and now I have to go back to that now, because you’re with a new person, you have to relive that bad experience with them (YCInt5).

Additionally, because this counselling was during school time, peers would’ve commented on whether or not they had attended and would ask questions which was very difficult for them; *“obviously you don’t want to be like ‘yeah, I go to counselling’”,* they went on to describe school peers falling out with her because she did not want to go into details about what she was going through (YCInt5).

5.3.6.7 Support at university

Two interviewees spoke of the support they received at university. One said they had received good support from a university tutor after they had sought it out, however they commented that there was no follow up from the tutor after their conversation, which left them feeling that *“they are very, very good at chucking out these words of wisdom, like ‘reach out if you are ever stuck’”* but that these words were of little substance (YCInt6). They believed they had received more support while at school. In contrast however, another commented that the support they received at university was more positive than their school experience. They recalled a time when while they were at university, coursework was due and things at home were difficult and they were *“cutting it really fine”* to get an extension (YCInt4). They described the reaction of the person who dealt with their extension and said: *“that was the first time I experienced someone saying I understand this is difficult for you- do not worry...”*. (YCInt4). Following this positive experience, for the rest of their time at university they did not find themselves in this situation again but based on their initial experience they were reassured that *“...if there was ever a time when things were bad again, I could speak to anybody”* (YCInt4).

5.3.7 The recommendations of young carers to help them be supported to fulfil their educational potential.

Interviewees gave recommendations that they believed would help young carers be supported to fulfil their educational potential. The recommendations they made fell into two areas, recommendations for educators and places of education and recommendations for young carers from young carers.

5.3.7.1 Recommendations for educators and places of education

1. Educators need to be trained about Young Carers

Three interview participants stated teachers needed to be educated about young carers. A training course was suggested to make teachers aware that they “might come across children like this” (YCInt5). Such training should include:

- What to do if a child comes to them and says they are a young carer.

- What to do with this information for example who to refer information on to, how to support young person.

2. Educators need to be sensitive in their reaction to a young person telling them they are a young carer.

Three interview participants commented on the importance of how a teacher reacts to a young person identifying as a young carer. making yourself vulnerable, you're opening up and I think people don't realise how their reaction to what you're telling them can have on you (YCInt5).

3. Raise awareness about young carers with pupils.

An interactive workshop was recommended as a means of educating school children and promoting understanding about young carers with a caring role (YCInt4).

4. Create a school environment where pupils know who to approach for pastoral help and promote a culture of talking about problems and feelings.

"I think having an environment in school, where people feel they can speak out or they can, you know, talk about these sorts of things and not see them as a negative, you know is another thing as well" (YCInt4).

5. Educators need to get to know their pupils.

With education...I think that teachers, every time a teacher meets a student, for the first time, every year you go you meet a new teacher- you are given a new teacher, there should be some type of form, some type of a holistic assessment, some type of thing with a tickbox...(YCInt6).

These findings have highlighted how young carers can find it difficult to disclose their caring role to their teachers/place of education. This does not need to be complicated; it could be as simple as asking a pupil in form class at the start of the academic year *"tell me a bit about yourself"* and is there anything you think I should know about you or your home life. Should an issue arise surrounding a young person, their form tutor and head of year could monitor that young person, checking in with them and advising that persons teachers on a need to know

basis. Such an exercise would need to be repeated by every pupil each academic year in case their circumstances change. Being proactive and giving young people an opportunity to share about themselves and their situation combined with being able to write their response and not to have to vocalise it on a one to one basis may help with the barrier some young carers face in regards to struggling to tell people about their caring role.

6. Specialist carer support.

One young person suggested a specialist counselling service for carers. This was based on their own experience of being in receipt of counselling services, they commented; *“I think people trying to be a general counsellor don’t always know, they’re trying to know a little bit of everything but it’s better when someone knows a lot about one thing”* (YCInt5).

7. The provision of study periods/opportunities for pupils either during school or afterwards but not during lunchtime.

This would provide young carers an opportunity and peace to complete homework and revision free from the demands of their caring responsibilities. One interview participant was adamant that they did not want to sacrifice their lunchtimes for such opportunities as they use then as an opportunity to socialise (YC3).

8. To encourage teaching professionals to look beyond the presenting issues with pupils.

One participant expressed concern that while they felt there was a lot of focus on mental health but little attention given to why a young person would be experiencing difficulties with their mental health. (YCInt6) The same they felt was true when it came to young people struggling at school, they highlighted *“that’s just an effect of what’s actually going on”*, they emphasised the need for schools to seek out the “actual reason” for a young person’s presenting issues.

9. Teachers need to exercise understanding and flexibility in dealing with young carers (YCInt1, YCInt2, YCInt4).

The comment was made that teachers needed to exercise understanding and flexibility when dealing with young carers experience problems completing homework's/coursework. It was felt by several young carers that teachers needed to realise that "you have other responsibilities outside of their subject" (YCInt1) that *"not everyone can prioritise school all of the time, because these people are still children and they are already sacrificing that childhood to help someone else and they shouldn't have to sacrifice more for school"* (YCInt2).

The types of understanding young people were describing as needed are as follows:

- *"...a bit more understanding about extensions over deadlines"* (YCInt4).
- *"...like probably, if they like understood you can't do homework's because you have been helping at home that would be better, that would be a big help"* (YCInt1).
- *"...expectations should be lowered for carers, not in the way that makes them feel like idiots...but enough that they do not feel pressured to always be perfect"* (YCInt2).

5.3.7.2 Recommendations for young carers from young carers

1. Inform your place of education about your caring role

This recommendation came from a young person who had not told their place of education about their caring role, they prefixed making this recommendation by saying *"I'm going to be such a hypocrite here, tell the school"* (YCInt2). Their advice, which gave insight into their own experiences, to other young people with a caring role was *"... and yeah it can be scary in case they don't believe you and stuff but like, it is worth the risk because you are not going to be sitting there in front of a GCSE paper and not being able to answer everything because you chose helping people over sleep- you know"*.

2. Try to have things (friends and time to yourself) outside of your caring role

The young person making this recommendation acknowledged;

"I know it's important but there are other things in your life to focus on, try not to focus every ounce of your energy on to your caring role because you are young and have a life and deserve to, this sounds really cringey, you deserve to shine".

(YCInt3) For example spend time with your friends, “*go to the cinema and treat yourself*” (YCInt3).

3. Find someone/somewhere you can go to for support about your caring role.

For example, a young carers organisation.

YCInt4, who made this recommendation commented that;

“...the one to one carers support that I received from that charity was amazing, it was really, really good....that was someone as well who was very knowledgeable about my situation and was very empathetic.... I suppose just having an outlet where you can go to just talk, is a big support” (YCInt4).

5.4 Findings from interviews with professionals

5.4.1 Background

Thirteen professionals, recruited from the three main young carers organisations, were interviewed in this study. They comprised seven Young Carers Project Workers, four Family Support Practitioners, one Young Carers Manager, one Young Person's Activities Facilitator. Their experience ranged from six weeks to between ten to twelve years (Table 15).

Table 15: Professional identifier codes and amount of experience working with young carers

Professional Identifier	Experience of working with young carers at time of interview
P1	9 years
P2	2 years
P3	7 years
P4	Less than 1 years
P5	2.5 years
P6	2 years
P7	6 years
P8	Less than 1 year
P9	9 years
P10	11 years
P11	4.5 years
P12	10 years
P13	2 years

Each professional, with the exception of P8, had experience of working with young carers aged 16 and over and had young people this age in their current case load. The minimum contact with each young person was once a month and for two of the organisations this was a requirement stipulated by the Health and Social Care Board, the service funder.

5.4.2 The educational experiences of young carers aged 16-24, from the professionals' point of view

5.4.2.1 Positive outcomes

Ten professionals shared examples of positive education outcomes for young carers with one revealing:

We have young carers hitting 3 A's at A-level and stuff like that, they're going on to do medicine, lord knows what country they choose because they can pick anywhere, cos you know it's phenomenal (P2).*

Eight professionals identified young carers who had gone to university, with one estimating: *"To be honest not many, not many that I've worked with in 10 years, I would say five out of those young people thinking off the top of my head. I'm thinking about five or six have gone on to university"* (P12). Some young carers physically moved out to attend university and others travelled as required-learning to drive being vital to this (P1, P3, P4, P13). One professional commented that university *"is a plan for most of our sixteen plus kids"* illustrating that young carers have this aspiration for their future (P4). Of those young carers known to attend university, many choose to pursue a caring profession such as nursing as well as teaching (P1, P3, P5, P9, P11, P12). Other examples of positive education outcomes included young people attending regional colleges to complete A-levels, BTec's, NVQ's and NVQ's or moving into employment (P3, P4, P7, P12).

5.4.2.2 Young carers' positive view of school

Focusing on academia was described as a *"solace"* for some young carers as *"their road to not be living at home...or not to be caught in that trap particularly with the mental health, drugs, alcohol ones"* (P9). Professionals described how young carers viewed school as a break, a safe haven from their caring role, the *"one outlet away from the chaotic life"* of a young carer where they can be *"a normal child, within the confines of nine to three, within the school setting"* (P5).

It was also put forward by a professional that some perceived by *“bettering their futures they can provide further support in the future if things deteriorate”* (P4). Another noted that just because some young people *“are not academically inclined...at the same time that doesn’t mean they aren’t having a positive experience of school”*, having understanding from teachers, being supported and having social interaction with their peers all contribute to making school a positive experience for them (P4).

5.4.2.3 Importance of a positive mindset

The importance of a positive mindset in coping with their caring role and education was observed and emphasised by nine professionals (P1, P3, P4, P5, P7, P9, P10, P11, P12) and was acknowledged as something dependent on the individual (P1, P4, P5). Elements of this mindset were:

- The role of resilience (P4, P7, P9, P10). They are not going to let their caring role stand in their way and will make the best out of their situation.
- The role of self-belief and self-confidence empowering them to achieve (P1, P 12).

Young carers were described as being able to be divided into two types in relation to their education; those who excel, are focused or driven to achieve, or who want a career helping people and those who are unable to cope and experience difficulties (P1, P5, P7, P9). P10 summarised what she believed contributed towards a young person having a positive experience of and positive outcomes from their education; *“...it depends on the young person, the situation at home, the support they have as to how well they get on and how they view their future and how they see their right now.”*

For those young carers who do not display this quality or motivation, it was suggested/queried by professionals if this was a result of them not having the opportunity to realise their potential, them wanting to be a parent and not work, family influence, no one to help motivate them differently or a cultural/family cycle of finishing school at sixteen. (P3, P12).

Two professionals spoke of young carers reaching an age *“where they will literally throw the head staggers and say ‘no, I’m not doing this anymore’ in terms of their caring role”* and want to, for example, go away to university or join the army (P7, P9).

5.4.2.4 Importance of/ Role of family support

Three professionals commented on the positive role of family support in young carers' experience of education (P1, P3, P10) which included: *"other family supports, people saying no you need to go to university, you need to do this, I will not hold you back"* (P1). An example was provided of a young person who provides care to their mother wishing to move away for university. This professional explained how the support of the mother has been important because *"she isn't saying to her 'what am I going to do when you leave' so they are already setting motions in place, so that wee girl can go"* (P10).

5.4.2.5 Young carers being supported at school and having a positive experience

Four professionals stressed the positive impact of young carers experiencing *"one good teacher, that can understand and emphasise what these young carers are going through"* (P2, P6, P9, P10). The opinion was that *"a good teacher will see you through, it really, really does"* (P10). Numerous professionals provided other examples of young carers being supported at school and having positive experiences (P1, P2, P4, P5, P7, P9, P10, P11, P12, P13).

Other examples of support included;

- The provision of part time timetables (P9)
- Access to a phone at break and lunch times (P9)
- Help with transport so young carers can attend extra-curricular activities (P9).
- To reduce stress on a young carer who had been threatened with detention due to their lateness they were allowed to write *"care of TEACHERS NAME"* in the late book so they did not have to explain their absence (P7).
- A professional described a school arrangement where they identified a place where a young carer struggling with anxiety could go to when necessary, and provided seating near a door during exams so if she needed to leave *"she could just go, she didn't have to walk past everyone"* (P5).

- Helping a young carer apply for special circumstances so they could have more time in exams and to complete coursework (P5).
- A school providing space for a young carer professional to come in and help support a young carer finding things difficult (P2).
- Allowing a young carer to use time within school to catch up on schoolwork etc that she was missing because of having to come to school late because of her caring role (P12).

5.4.3 Professionals experience of young carers having problems with school/education

5.4.3.1 Lack of understanding, support, and awareness about young carers in their place of education

Eight professionals spoke of young carers experiencing a lack of understanding, support or awareness in their place of education (P1, P2, P7, P9, P10, P12, P13). Examples given by professionals included teachers not realising the role and possible impacts of being a young carer and instead, in some instances, seeing it *“as an excuse to get out of something”* (P10, P12). When a young person had to take several weeks off school due to his caring role, falling behind with his work, his non-attendance was attributed to him being *“a problem child”* and no support was given (P13). P7 gave the example of a young carer who was frequently late or absent due to providing care to her mother and siblings, who was told by her Principal that she was not allowed to attend her school formal because of her lateness and absence (P7). This was despite the school being aware of her caring role.

Professionals spoke of young carers having to tell and retell teachers in their schools about their caring role, that they were either having to explain their situation to different teachers or remind teachers who have already been informed (P10, P11). They described young people as reaching the point where they *“don’t feel like they are being heard”* (P10). This feeling of not being heard or listened to was illustrated by one professional who said;

...and even if situations do crop up sometimes the teacher would say ‘I promise this will not happen again, why didn’t you tell us you are a young

carer?’ Whereas we are like ‘we have’, letters have been sent.... So, it is constantly just repeating and repeating and nobody is obviously listening. Nothing changes. (P10).

P12 provided an example of a teacher being informed about a young person’s caring role and arrangements being made with the school for them to hand in work late; however, when the young person informed their teacher that they had an extension, the teacher claimed no knowledge of this and *“kinda laid into her a wee bit in class in front of everyone and the young person had to say in front of the whole class ‘well you know my mums not been well’”* (P12).

Professionals gave examples about how young carers’ experiencing a lack of support impacted on them (P2, P9, P13). One described a young carer who was *“a really smart young person”*; however, he did not receive support from school, was negatively *“labelled”* and left school with a lack of qualifications (P13). It was perceived his outcomes would have been different had he been supported as he had *“every potential to do anything that he wanted to do”* (P13). There was a belief amongst some professionals that schools placed more importance on exam results and league tables than providing understanding and support to a young carer (P2, P9).

Several professionals described school as being a cause of significant stress for some of the young people they worked with (P5, P9), with one disclosing that three young people from their caseload, were receiving treatment from CAMHS and *“citing difficulties at school as one of the reasons they are feeling so stressed”* (P5).

Professionals reported some young carers do not want school, teachers or their peers to know about their caring role (P2, P3, P4, P5, P7). They felt that schools not knowing about a young person’s caring role was detrimental to that young person, one professional went so far as to describe a young carer they were working with as being *“her own barrier to a solution”* (P4). For organisations to make contact with a young person’s school this requires them to consent, if they do not consent to it, they cannot break confidentiality and do so (P2, P4).

5.4.3.2 Balancing caring role and the completion of schoolwork

Professionals referred to the balancing role young carers face between their caring role/home situation and their education (P2, P11). One commented that “[T]hey didn’t have a lot of time that wasn’t school or caring” (P11). An example was given of what some young carers experience balancing their caring role and education;

...going home from school, getting your homework done, you go home and you have to start dinner, the washing so some young carers we find are doing thirty hours plus additional to their full time education, so that’s like doing a full time job going home and having a full time job and homework on top of that (P2).

Difficulties completing schoolwork (that includes homework, coursework and revision) was highlighted by many of the professionals (P1, P3, P5, P7, P9, P12, P13). Several reasons were given for this: them not having as much time to utilise for homework etc or too much else to do when they got home from school (P1, P3, P9). Some were unable to get peace and quiet to complete homework/coursework (P5, P7, P12, P13). Others may not have “as much enthusiasm from parents to push them to go and get that homework done” or they may just be too stressed (P1, P3, P7, P11, P12). One professional outlined how difficulties completing homework could, for some young carers, cause worry about going to schools whilst for others, it could lead to non-attendance: “...lots of young people who then don’t have their homework, rather than going in and face the music or explain the situation because they don’t want to, they are too embarrassed, they just don’t go” (P9).

5.4.3.3 Young carers and the future

Professionals identified several obstacles faced by young carers in terms of their future prospects. Firstly, in relation to them making decisions regarding their future based on their caring role (P10, P11, P12, P13). For example, not wanting to move away to university or choosing to take a job close to home. Secondly, having restricted options because of their caring role. This could be because they

wonder who will provide the caring role if they do not (P13) and/or them not wanting to leave home because of their caring role (P5). P5 provided an example of a young person wanting to go to university but wanting to remain living in the family home. In this instance the professional commented referring to the young person's choice of academical institution; *"she will travel, and she will end up traveling a lot because she doesn't live anywhere near where she wants to go"* (P5). Thirdly, a young person falling into *"a trap"* of thinking it was easiest for their caring situation to stay at home (P9). The professional raising this revealed they had two young people on their case load who had decided not to continue their education for this reason. Fourthly, young people not reaching their full potential (P12). One professional depicted that they had experienced young people who they knew *"that they are capable of so much more in their career and have so much talent, sometimes I feel they have just gone out and got a job in the chippy, you know, because that's all they can kinda manage to do"*. Fifthly, some experiencing a sense of hopelessness about their future, thinking there was no point continuing their education (P6). Sixthly, feeling restricted by their perception of their caring role which may not be reality (P7). The example was given of a young person who *"had it in her head 'I cannae' go because I need to be here for that, that and that...whereas that is not how the family perceived it that way at all. They were like she's a great help"*. The seventh and eighth obstacles identified were family influence and lack of qualifications, these will be discussed in separate focused sections of the same title.

One professional outlined how for one young carer it was not their caring role that caused them difficulties obtaining a place on a training scheme which sought to mentor young people and help them secure full-time employment. In this instance, the young person was not eligible for this scheme because they had a part time job which they used to help support their mother who they provide care to. The professional felt that had the criteria for the scheme been different this would have been a brilliant opportunity for this young person as they were looking for a career path.

5.4.3.4 Problems with transition

The problems some young carers face transitioning from school to other forms of education, for example, to a further education / Regional College was addressed by two professionals (P6, P9). Such problems included worry about who would look after their cared for person while they attended classes, young people having to overcome a sense of hopelessness they feel in relation to their situation, and adapting to the expectations of universities or Regional Colleges where students are expected to take personal responsibility for their attendance, completion of homework and self-motivate (P6, P9).

5.4.3.5 Low grades/lack of qualifications

Five professionals considered that low grades or a lack of qualifications had been the result of a young person's caring role (P2, P4, P7, P9, P13). Describing one young person, P13 said *"he just didn't attain good results because he missed so much"*, and although he went on to college he *"didn't complete it either because of the responsibilities at home"* (P13). Another example was given of a young carer whose grades dropped from A*s to C's after their mother had been hospitalised long term; when asked by their support worker why they thought this was, they said it was down to worry.

One professional explained why they believed some young carers do not achieve as well as their contemporaries;

they don't achieve as well as their peers...and that is down to a lot of the time to their attendance at school has not been as good as it should be. They aren't supported as well in school, I don't think a lot of the time em and not having the space to study or revise or quite simply they are just too stressed and school isn't up on their agenda, education isn't on their agenda (P7).

5.4.3.6 Family influence

Family influence having a negative impact on a young carer was mentioned by five professionals (P1, P3, P6, P9, P11, P12).

Two spoke about them feeling guilty about leaving the person they are caring for and parents being unable to, perhaps due to their own illness, to say to their *child* “*I will support you*” or “*this would be good for you*” rather than telling them they are needed at home, which would help alleviate feelings of guilt (P1, P9). Linking further to this, four identified that some young carers do not receive the necessary motivation and encouragement they need, as perhaps due to their illness, parents are “*not always able to prioritise their children’s needs*” (P1, P3, P9, P11, P12). P3 commented that “*maybe parents don’t have, with their mental health issues, don’t have the time, energy, understanding to try and push their children when it comes to their exam times and things like that*” (P3). Showing how a young person can be affected by this, the example was provided of a young carer providing support to her mother with mental ill health, who wanted to go to university in England. The professional commented that;

...it just feels that mum is finding excuse after excuse to not support, so the young girl herself to me the other day, it was just like ‘I’ll not be able to go’ and was drawing the line there (P12).

Two professionals mentioned young carers sometimes adopting a parent or other cared for person’s behavioural issues or traits (P3, P9). For example, a young person developing a “*well I won’t be able to do that-poor me*” attitude, P9 described “*a lot of those ones who are going this path, they almost have developed their own mental health issues, it’s really hard to get out of that cycle*” (P9).

The idea of susceptibility to repeating a family cycle of behaviour was raised by P3 who spoke of young people maybe not wishing to work or go further with their education because that has not been what their family traditionally has done. This in to addition to the impact of the location or culture in which the young person has been raised, for example perhaps where they were raised the culture or practice was for them to leave school at sixteen, “*hang out in the house*” or start a family of their own (P3).

5.4.3.7 Worry and concentration problems

Professionals outlined examples of young carers experiencing worry and concentration problems while at their place of education (P4, P5, P9, P12). P5, provided an illustration of how worry and concentration problems can impact on a young carers school day;

...the common theme is that they wake up and there's lots of stuff going on in their house in the morning and they've got responsibilities or they know there's stuff going on during the day when they are at school and they go into school and they worry and they don't hear a word that the teacher says and then they worry the whole way home because they don't know what they are coming back to (P5).

5.4.3.8 Bullying and Isolation

Bullying was raised by nine professionals as being an issue faced by young carers (P1, P2, P3, P4, P5, P9, P10, P12, P13). One professional commented that in the two years they had been in their role, in two out of three assessments they had completed with young carers they said they are bullied at school (P5). The bullying being faced by young carers was not necessarily always down to their caring role (P1, P3, P4, P5, P13). In the situations where a young carer being bullied was associated with their caring role, they faced bullying about the condition and/or appearance of the person they provide care to (P4, P9, P10). Personal qualities, issues or situations stemming from the young person's caring role could also be a motivation, for example their personal hygiene, being sensitive or due to family finances they may not be able to afford brand name clothes etc (P3, P10). P9 believed that social media sometimes contributed to this bullying- *"if the whole world knows what's going on with a person's family, like particularly if it's drugs, alcohol, mental health"* (P9).

Young carers experiencing feelings of isolation in school because of their caring role were also raised by three professionals (P5, P6, P8). One described some young carers as being *"socially isolated more than educationally impacted"* (P8). The reasons given for this included not feeling able to bring friends home

because of their cared for person and the young carers being more mature compared to their peers. P5 gave an example of a young person who they described as;

very much an outsider in school. He was a lot more mature than his peers; he couldn't relate to them, he didn't like when they called children with disabilities 'retard' or other names so he distanced himself from everybody (P5).

5.4.3.9 Non-attendance and lateness

Non-attendance was highlighted as an issue for young carers by eight professionals (P1, P2, P4, P5, P7, P9, P11, P13). One professional commented that *"having a caring role, there is a barrier to access, actually physically getting to school"* (Prof 2). P9 revealed the extent of non-attendance amongst those young people on their caseload, when they said out of the twenty young carers, they worked with aged sixteen to eighteen, eight of them were non-attenders. P7 stated that two of the young carers they worked with did not attend school but had home tuition instead. Professionals offered several explanations as to how this was the case. Their parent may not be able to get them up to go to school in the morning and encourage/motivate them to attend (P1, P7, P11). (Three professionals described cases they had come across where this was the case, two involving a young person caring for a parent with mental ill health and one involving a young person caring for a parent with both mental ill health and drug misuse issues). The behaviour of, or medical condition of a young person's sibling may impact on a young carer physically travelling to school (P4, P5). The example was given of a young carer whose brother was *"extremely volatile...with his challenging behaviour"* and during a bad week she would not get into a car with him (P4). They may not want to leave the person they are caring for because they worry about them while at school and or do not trust anyone else to look after their cared for person the way they do (P1, P5) (P5 provided an example of a young person in this situation who felt this way despite their mother, who they provided care to, encouraging them to attend). A young person may be too tired to go to school due to the caring role they have performed overnight (P1). The young carer may have their own mental ill health problems relating to going to

school (P5). It may not be viable for the young person to attend school because of their caring role (P2). P11, highlighted that for some of those young people missing school because of their caring role *“the longer it as left the more of an issue it was and the more work they maybe fell back on”* (P11).

P9 conveyed concern over young carers not receiving their EMA as a consequence/result of having to take time off from their education to provide care. Their concern was *“if they take one day off and lose their weeks’ pay, they’ll say sod it, I’m not going in the rest of the week. Then that starts that kinda ball rolling”* (P9).

At least four professionals spoke of working with young carers struggling to get to school on time because of their caring role (P1, P2, P5, P7). The majority of the examples given outlined young carers facing problems and a lack of understanding at school due to their lateness. One professional commented that a lot of the young carers they work with would rather not go to school, than go to school late (P1).

5.4.3.10 Dropping out

Young carers dropping out because of their caring role was touched upon by several professionals (P7, P13). P7 provided examples of young carers they had worked with aged fourteen and fifteen who had dropped out of education to provide care for their mothers, following the onset of sudden illnesses. They disclosed that both these young people had since re-engaged with education, however they also acknowledged that this hasn’t always been their experience when young people pull out of education, that not all re-engage or go into employment some remain providing a caring role.

5.4.3.11 Need for earlier intervention

Two professionals revealed that in some instances it was only when a young carer reached crisis point that they asked them to approach school with them for

help (P6, P9). P9 went further *“it’s usually crisis to crisis that we are working on”*, they estimated that eight out of ten times the crisis the young person was experiencing was related to education (P9).

Professional 9 also commented that especially for those young people caring for someone with mental ill health or who misuse drugs or alcohol, early intervention could be beneficial, this professional believed if they received a referral for a young person in this situation aged seventeen; *“it’s nearly nigh on impossible to change the way they think and we could’ve done with them earlier to build resilience and coping skills and give them understanding about what’s going on at home”* (P9).

5.4.3.12 Issues outside caring

One professional commented that sometimes for young carers, their education is not impacted by their caring role but because they have “their own issues”, they gave the example of a young person attending an all-girls school and struggling with/questioning their sexuality (P1).

5.4.4 The experiences of professionals building relationships with schools

It was logical to ask professionals from young carers organisations about their experiences of building relationships with places of education, due to the age of young people on their caseload. All young carers organisations in Northern Ireland, offer awareness raising talks or training that is tailored for the group it is requested for.

5.4.4.1 Positive experiences building relationships with places of education

Overall, on the subject of building relationships with schools, eleven out of the thirteen professionals reported some type of positive interaction (P1, P3, P4, P5, P6, P7, P9, P10, P11, P12, P13). P7 described some schools as being very responsive, P9 however was of the opinion schools were getting better in terms of understanding and supporting young carers, and referring young people identified as a young carer to a young carers organisation.

There was the belief amongst some professionals that some schools were better than others as to how they dealt with young people identifying as young carers (P3, P9, P13). One professional felt that schools in the area in which they were based were “*specifically...really good*”, this was in reference to the pastoral care systems in place which included the utilising of outside organisations to provide mentoring and counselling to pupils in need (P3). P9 explained that such variations they were experiencing between schools did not, in their opinion follow a pattern in relation to the type of school involved; “*... some schools are good and some schools are not. And I can’t say it’s the Grammar schools that are bad or the, you know, other ones, it is really a kinda mixture*”.

Positive experiences of professionals building relationships with places of education can be grouped into two categories: a teacher or school being proactive on the subject of young carers and professionals advocating on behalf of young carers to their place of education.

Five professionals talked of individual teachers or schools being proactive, seeking and/or providing support to young carers (P5, P6, P9, P11, P13). Examples of how this proactiveness manifested itself included the establishment of a young carers group within a school, invitations to attend school fairs or talk in assemblies to raise awareness of young carers, referring young carers on for counselling, contacting a young carers organisation to find out further information about the services provided and referring a young person to such an organisation. An example was also given of one organisation in the past providing teacher training at a teacher training college. Seven professionals provided examples of their experiences advocating on behalf of young carers to their place of education

(P1, P4, P5, P10, P11, P12, P13). There was the opinion that when a place of education was approached and told about a pupils caring role they were accommodating and information was positively received and feedback sought (P1, P4, P5, P10, P12, P13). P12 commented that;

I think once you ring a school and explain what is going on, most of them are very open to me coming in and certainly I've had experiences where they are like 'you need to tell us more about what this means for the young person and you need to tell us more about the young carers service'.

Four professionals (P1, P7, P9, P11) spoke of having positive relationships with EWO's and of working together to support those young carers in their shared remit. The only criticism raised was that once a young person turns sixteen years old, they are no longer under the remit of the Education Welfare Service(P9).

A number of professionals referred to the advice booklet 'Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff' (HSCB, 2017) (P1, P5, P6). Moving forward building relationships with schools, a professional summarised the feelings of professionals on this topic when they said *"[t]he schools' booklet, we are hanging a lot of hopes on that"* (P6). Professionals hoped that this document would be used to distribute information amongst teachers in schools, providing them with advice and how to access support services for young carers.

5.4.4.2 Difficulties building relationships with school/place of education

Eight out of thirteen professionals spoke animatedly and passionately at length about difficulties they had experienced building relationships with schools/places of education (P1, P2, P4, P5, P7, P9, P10, P12). Seven professionals spoke of experiencing difficulties either making contact with or gaining access to teachers in school (P1, P2, P4, P7, P9, P10). The following quotes represent the extent of their feelings on this subject;

- *"we have found great difficulty getting into schools. I don't know if the rest of them mentioned that, getting into school is a nightmare"* (P1).

- *“...depends on the school but honestly I would find them that they think we are a little bit of a nuisance, you know we aren’t really met with pleasantries as such, it’s kinda like ‘what do youse want us to do about this’” (P10).*
- *“It’s just getting through to them, we are hitting our heads through brick walls and getting nowhere, so I find if you ring them up and you leave a messages they don’t reply to your messages, so you have to keep hounding them, you have to keep ringing and you have to keep ringing until someone finally takes your call. Pure just because they are fed up of you ringing” (P10).*

Three professionals described difficulties getting educators to attend events about young carers (P2, P7, P9). P9 gave the example of a time when their organisation received funding from the Education Authority to highlight young carers to schools and the organisation engaged retired principals to deliver workshops to teachers. Invitations were sent to a significant number of principals and school pastoral care staff and venues organised in several areas to accommodate approximately one hundred attendees at a time. This professional attended two such workshops to provide support to teachers and reported only six teachers turned up at each. P10 expressed the same opinion that attendance at these same events as *“very very poor”*. P2 when describing their experience of delivering teacher training days, said they felt *that “they didn’t want to really know about, didn’t think it was part of their job, there was a real attitude towards learning and receiving this sort of education”*. P7 referred to a project they worked in partnership with a drama group to make a film about being a young carer. This involved young carers from twelve different schools, with school principals consulted throughout the production process as young people needed excused from school from two days to participate. Upon completion, invitations were sent to principals and other professionals to attend the film premiere. This professional expressed frustration that;

not one, not one person from a school came and there were twelve young people involved....not one person from education, there were social workers, there was different...there actually were people from CAHMS there, but no schools, no schools represented. In fairness it was half term, but it was just a wee bit disheartening.

Professionals had various opinions as to why they experienced these particular difficulties (P1, P5, P7, P10, P12). Some believed that schools were scared *“about opening a can of worms”* on what could be a potential child protection issue (P1). Professionals described interactions with teachers who believed issues surrounding young carers as amounting to neglect (P10, P12). In one instance, following an awareness raising with teachers, a professional told that the reaction they had received was *“this fear of child protection issues”* (P12). Another professional speaking of a similar experience said in such instances teachers felt that making a referral to social services was enough, this professionals felt *“that was them passing the buck...not putting procedures in place to help that young person at school”* (P10). Others talked about teachers/places of education having curriculums to cover, that they are under pressure with that and do not have the time for one more thing (P1, P5, P7, P10). Three of the professionals were sympathetic to the workload of teachers. One acknowledged the pressure on teachers *“to identify everything with every young person in the school”* (P5). Another commented *“I know they are completely overwhelmed and swamped with everything but it is such a prevalent issue at the moment that it can’t be ignored any longer”* (P10). Another reason was the belief that for educators *“ignorance is bliss”* (P7).

One professional felt that the actions of a school had made it difficult to help a pupil they were working with, who would have had anxiety trying to go to school. The professional approached the school to ask would it be possible to have space to have a coffee with the young person before classes to help settle them. To do so, they had to email the principal for permission, provide ID and send verification from their manager however, they never received communication to verify whether or not they could proceed with this, by which point the young person was officially on study leave. The professional said *“I was very disappointed with that one, it was just like they didn’t believe who were”*(P12).

P2 communicated their experience of having a school questioning the legitimacy of a young person having a caring role due to their family make up, receiving the comment *“I fail to see how he is a young carer whenever he has a mother and father at home”* (P2). This disbelief was something they said they, along with their colleague, had experienced before and provided the additional example of them and their colleague attending Looked After Children (LAC) reviews and schools

stating they did not have any young carers in their school, when they knew they had several young people on their caseload attending that school.

P9, gave examples of interactions with school staff that illustrated ignorance of what a young carer was and a less than adequate response to a young person with caring responsibilities. They described being referred to as *“the lady who worked with the poor people”* (Prof 9). P9 described sharing with a school about a young person’s situation and asking for understanding on their behalf and of how a teacher *“actually turned around, and said ‘people like that, people like that’”* (P9). They shared that they had been approached by a teacher regarding a child protection issue with a young carer that they did not want to refer to social services, so the professional had to take this action instead. Additionally, the example was given that instead of being motivational to a young carer who was academically coping but not coping as well emotionally, they were told by a teacher *“I wouldn’t bother doing your UCAS because I don’t think you will manage it”* (P9).

This same professional illustrated how they had approached every High School in their area, explaining who they were, what young carers are and how they can have problems completing homework’s at home. They asked for the use of a room within the school weekly or fortnightly where young carers could be aware that there would be someone there to talk to or utilise having a quiet place to work. This professional actively wanted to liaise with schools, working in partnership with them but not one school responded to this offer (P9). From their experience partnership happened with schools once a crisis had occurred in the young carers situation and they stressed the need for early intervention so young people can be equipped, empowered and encouraged.

5.4.4.3 Professionals identifying a need to educate places of education about young carers

Six professionals said they felt places of education needed to be educated about young carers to raise awareness (P1, P5, P7, P9, P11, P12). For example, P1 commented *“I feel that it’s important, schools need educated. Every school will have a young carer in them at one point, and it’s important that they know how to work with them to support them”*. P5 acknowledged that schools and teachers

face *“a lot of pressure on them to identify everything with every young person in the school...but I think there needs to be a bit more awareness of it and what they are doing at home”*.

Three professionals observed that they had not received significant numbers of referrals to their young carer's organisation from teachers (P2, P4, P10). P4 revealed that not one referral received by their organisation came from a school, they commented; *“Schools see young people nine to three most days, five days a week, they have the most contact apart from anyone outside of the family home and we've not received a single referral for them”*. They remarked *“the fact we have none referred to us from them is a disgrace”* (P4). This professional mentioned they believed there were several explanations for this, staff were *“oblivious to the needs of young carers”*, staff were identifying young carers but not wanting to raise it with families or *“they can't be bothered doing the paperwork”* (P4). Their belief was, should schools identify and refer even some young carers as per NI Census figures, young carers organisations in Northern Ireland should be *“unable to cope with the demand”*. Another option raised was that teachers just did not have the time to refer. P2 revealed only one percent of referrals to their organisation came from schools (P2).

5.4.5 Recommendations of professionals to help young carers fulfil their educational potential

Each professional was asked what recommendations they would make to help support young carers aged 16-24 with their education. Overwhelmingly, they recommended that Educators need to be trained about young carers and educators and places of education should respond to young carers in a way that is both understanding and supportive. Following these, the remaining recommendations are grouped around themes.

Educators need to be trained about young carers (P1, P2, P4, P5, P8, P 9, P13). *This recommendation was the most frequently mentioned by professionals.* It was recommended this training should include awareness raising and information on how to identify and support young carers. Two professionals

recommended that such training should form a part of initial teacher training at university (P2, P9).

Educators and places of education should respond to young carers in a way that is both understanding and supportive (P1, P4, P7, P9, P10, P11, P12). P10 summarises how they felt educators and places of education should respond to young carers when they said;

for those young carers who do need that extra bit of support, I do feel that that should be given to them, you know without any question, without having to prove themselves, without having to repeat themselves, without being passed from pillar to post from teacher to teacher and constantly going over that, the same way there is with everything else. It should be on their file, it should be noted from day one that this person is a young carer (P10).

P9 emphasised how *“just being kind and listening to someone can make such a difference”* and urged teachers to *“teach children, not subjects”*.

Recognition by the Education Authority that young carers are a group of young people that schools/places of education require specific training on (P2). In other words, a top down approach to supporting those with a caring role within education.

Places of education should utilise the document ‘Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff’ collectively produced by The Health and Social Care Board, The Education Authority, Action for Children, Barnardo’s NI, Carers Trust NI, The Children and Young People’s Strategic Partnership, Young Carers Regional Sub-Group and GingerbreadNI (HSCB, 2017).

The promotion of informal education opportunities alongside traditional education pathways for example The Princes Trust, OCN’s, training and employability schemes for young people with a caring role who may be having

difficulties fulfilling or achieving what is required/expected of them with more traditional educational routes (P2, P7).

Places of education and young carers organisations working in partnership to support those young people with a caring role (P3, P5, P9). Such a partnership should not be the result of a crisis, instead it should centre on early intervention.

Places of education using outside organisations for example charities to support their pastoral care strategy and staff (P3, P5). In addition to the above recommendation of partnership between places of education and young carers organisations, the additional areas it was suggested outside organisations could provide support to places of education included counselling and mentoring.

5.4.5.1 Practical ways of helping young carers within education as recommended by the Professionals.

Enable them to have access to a telephone while at their place of education (P1, P4, P5, P13). This could take the form of allowing young people with a caring role to keep a mobile phone on their person while in class or permit them to leave class to make a call as a means of alleviating any worry they may have about their cared for person while they are in their place of education.

The provision of a Card or some other visible indicator that a young person could show a teacher to alert them that they are a young carer (P2, P5, P6, P10). This would be helpful in those instances when a situation (for example lateness) has arisen as a result of their caring role and they would like either to speak to the teacher after class or have time out of class to compose themselves. The idea of an anxiety pass was also suggested (P5).

Permit extra access to computers if required (P10). P10 felt for young carers from families facing financial difficulties, where perhaps a parent or both parents was unable to work they should be *“given a little bit more access to computers so they can achieve the same as their peers but they don’t have the same facilities at home to do so”* (P10).

Flexibility around deadlines for homework or coursework completion with young carers aware of and educators willing to utilise the option of applying for special circumstances from an exam board should a young person's situation require it (P13, P5).

Education professionals using the option of excused absences for those young people missing school because of their caring role to reduce impact on their EMA (P5). One professional suggested young carers be given "*carers days*" like they would receive in their place of employment.

Specialised careers advice for young people with a caring role, that includes educating them about their options and rights (P7, P8, P12). Such advice would be based on an understanding/sensitivity about the young person having caring responsibilities at home and include more support for them applying for part time jobs, colleges etc utilising the skillset they have gained through their caring role. One particular professional felt it was important to highlight to young carers that "*that there's more to life than caring*" (P8). Their fear was that after the age of 16, a young person did not legally have to remain in education and they could feel they could or should become a full time carer, being unaware of the education, employment or support options available to them.

More support for young carers post 16 (P8, P9, P12). This echoes in part what was outlined above in relation to a specialised careers service for young carers. It was raised how EWO's stop working with a young person at the age of 16, leaving then with no such support (P9). Another professional believed this particular age group needed "*mentoring or guidance, not necessarily someone to advise them to pick this or pick that, but someone who can help them think and someone who can help them make decisions*" (P12).

Regarding the provision of pastoral support to young carers in education, the following suggestions were made;

- **An identified person/teacher** for them to go to (P12).
- Places of education having a **Young Carer Specific Policy** (P10).
- **Young people have a means of accessing pastoral support “without drawing attention to themselves”** (P10). Rather than having an appointment system where young people would be either summoned from class or have to ask to be excused, what was suggested was a ‘drop in’ option.
- **A focal point within places of education so young people can see what support is available both in house and from outside organisations** (P5).
- **The provision of peer to peer support groups in school** (P13).
- **The use of a worry box** where a young person could write a brief description of what is concerning them, and a teacher or support services worker could talk to them about it and organise/provide any necessary support (P1).
- **Provision of a safe place where they can go to if they need to speak to someone** (P11). One professional mooted the idea of young carer professionals having offices within school so young people can have easy access to them (P9).

5.5 Conclusion

This chapter has outlined findings from the three sources of data collected from young carers and professionals throughout this research project. This data has provided information about; the caring roles young people are performing; their attitudes towards education; their experiences of education, the relationship between their caring role and education; the types of support they have received and what young carers and professionals would recommend to help support young carers in education in the future. Professionals also detailed their experiences of building relationships with places of education. What will now follow in Chapter 6.0 will be a discussion of the key research findings, policy and literature.

6.0 Discussion

6.1 Introduction

At the core of the research findings is the acknowledgement that the situation and experience of each young carer is individual and while generalisations can be made, assumptions cannot. Findings have given unique additional insights into the educational experience of young carers aged 16-24 in Northern Ireland and identify a clear need and scope for further research on the subject. They have detailed the complex, varied ways in which having a caring role has (or has not) impacted on their education and future options, and further information has been gained about the support young carers have received with their education. It has also provided young carers and professionals an opportunity to voice how best their educational potential can be fulfilled.

6.2 Theoretical approach

Having analysed the data, it was apparent that after a critical examination of the findings using Bronfenbrenner's Ecological Model (see Chapter 1) would be best represented in an adapted framework that comprised three key layers – the micro, meso and macro.

The young carer remains at the centre of this adapted model. Within their *micro-system* they have several roles. At home they are a child, a carer, perhaps a sibling; they have responsibilities, expectations and obligations in each of these roles. At school or other places of education, they are a pupil where their focus is expected to be on learning, the completion of schoolwork and exams. Some may also be a service user of a young carers' organisation, depending on age, criteria or personal choice. Within a young carers' *meso-system* the influence of home, family, school and support experiences is evident. This includes the impact of their caring role on their education experience as well as the impact of any

support they may or may not have received. The final layer is the young carers *macro-system* which is shaped by the policies, strategies and legislation in place relevant to them.

In this chapter, the adapted model will provide a structure through which to discuss the findings. However, it must be emphasised that the levels contained within it are not rigid; this is a fluid, porous model with much interplay between and through the layers. Therefore, the flexibility of this model mirrors the circumstances and experiences of young carers in relation to their education.

6.3 Micro-system - the young carer

At the micro-level, the findings have drawn attention to the reality of the situations faced by young carers. They have emphasised how much of an individual experience it is for each young carer - be it in regards to who they provide care to, the condition of their cared for person, how many people they provide care to, what their caring role entails, how many hours a week they provide care and the duration of time they have provided care. . When this is considered, even before examining the impact of their caring role on all other aspects of their life (be it personally, socially or educationally), we see highlighted the variation between and the spectrum of young carers experiences that exist.

The key findings at the micro-level concerned the positive attitude young carers have towards their education, the importance of a positive mindset, their place of education as a haven from caring, and their mixed feelings about whether or not they want their educators to know about their caring role.

The majority of young carers in this research agreed that they had a positive attitude towards their education (65.5% of survey respondents and five out of the six young carer interviewees), education was important to them, they wanted to succeed and they are ambitious. This same attitude was identified in the literature

from GB, Africa and Australia. Here several reasons were presented or suggested as contributing towards this positive attitude including resilience and determination and the view that succeeding educationally was acknowledged as a means of improving their own and their families lives (Smyth et al., 2011; Cass et al., 2009; Evans and Becker 2009; Eley, 2004; Thomas et al., 2003). The researcher's experience of the young carers she came into contact with throughout this research was very much that outlined by Thomas et al., (2003) when they were "struck" by the positive attitude displayed by the young carers they encountered towards their education (p.40).

Such a volume of young carers reporting a positive attitude towards their education despite the sometime difficult circumstances they are facing, is something that needs to be nurtured and encouraged by educators and those working to support young carers, to help support them in terms of reaching their full potential and in fulfilling their ambitions, as well as practically supporting them in their role as a child carer in education. This is not a new idea, Article 29 of the UNCRC states that education "must develop every child's personality, talents and abilities to the full", part of achieving this has to include a focus on the mental health and well-being of young people, building resilience and coping strategies such as that promoted by the DE iMatter Programme (2018). However, it is one that needs to be emphasised within the education system as the research has demonstrated disparities in the levels of support and understanding that participants felt they had from their school.

This positive attitude towards education links to the importance of a positive mindset to cope with having a caring role and being in education. This was highlighted by a significant number of professionals who had witnessed it in the young carers they had worked with and half of those young carers interviewed. This positive mindset was described as dependent on the individual but was categorised as resilience, self-belief and self-confidence which provided a stable foundation on which to foster their motivation to persevere with their education.

Similar findings have been referenced in the literature (Evans and Becker 2009; Eley, 2004; Thomas et al., 2004) where young carers success in education was partly attributed to individual “high aspirations...interest and motivation” (Evans and Becker, 2009, p.199). This raises the question where does such a mindset originate from? Is it something that some young people possess naturally, or is it something that is a product of the young person and the impact of the support network they have (Cassidy et al., 2014). Can it be attributed to the encouragement the young carer receives from the person they are caring for? Is it something that can be cultivated amongst young carers via professional support? It could be suggested that it is a composite attribute that comprises one or more of these suggestions, raising the question does having more than one of these increase a young carers resilience? This could be a potential area for future research.

The concept of a place of education as a break from the caring role- featured strongly in the literature (Szafran et al., 2016; Cluver et al., 2012; Szafran and Duerkson, 2012; Barry et al., 2011; Evans, 2011, Smyth et al., 2011; Moore et al., 2009; Lackey and Gates, 2001; Gates and Lackey, 1998). Here school was referred to as a form of respite and a sanctuary from caring responsibilities. The findings of this research confirmed this sentiment amongst young carers in Northern Ireland, with over two thirds of survey respondents agreeing that they felt free from their caring role while at their place of education (69.0%) and a higher proportion (79.3%) agreeing that their place of education offered a break from their caring role, a view also reinforced in interviews with professionals. The literature identifies possible reasons for this: their place of education was somewhere exclusive away from their caring role, somewhere to be social and make friends - especially for those young carers unable to socialise outside of school (Cluver et al., 2012; Barry et al., 2011; Smyth et al., 2011; Moore et al., 2009). However, this was not the case for all participants. As also identified in the literature (Szafran et al., 2016; Thomas et al., 2003), several young carers (21.4%) in the survey identified their place of education as adding to their problems. McAndrew et al., (2012) offered some explanation for this in that for some young carers, school can be a place associated with insecurity particularly if they do not feel supported or experience bullying. These findings highlight that

places of education are regarded by the majority of young carers as somewhere they feel free from, and have a break from their caring role, and therefore emphasises why it is important that steps are taken to ensure all young carers receive a positive and supported experience while at their place of education, to help them fulfil their academic potential and reduce any negatives educational impacts of their caring role.

This research reported that young carers have mixed feelings about whether they want their educators to know about their caring role. Survey results showed no difference between those who wanted their educators to know (37.9%) and those who did not (37.9%). Equal numbers of respondents (37.9%) also revealed whether their teachers were aware or not about their caring role. Literature elsewhere in GB provided some insights into why young carers do not wish their school to know about their caring role. These included a desire to keep their home and school life separate, uncertainty about trusting teachers with the knowledge of their situation (Barry et al., 2011), or not wishing to be identified because of fear of stigma (Szafran and Duerksen, 2012; Robotham et al., 2010). Additionally, four interviewees in this research revealed that they either struggled to tell their teachers about their caring role or were scared about how they would react, another did not feel that their caring role was an issue with their education and that was why their educators were not informed. Professionals interviewed emphasised that it was detrimental to the young person if their place of education was not aware of their caring role. These findings highlighted two opposing positions on this subject, both equally valid - those who want their educators to know about their caring role and those who do not. The reasons presented as to why this is the case could indicate that young carers are not a group recognised within a school context. Should young carers have such recognition and information about pastoral support be readily available, it may help cultivate and promote an environment in which young carers feel they can be open about their caring role.

6.4 Meso System - Impact of caring role on education and support received

At the meso-level, the complex nature of both the situations and experiences of young carers is highlighted. The focus of this section will be on how, and to what degree, these young carers' education was impacted by their caring role and why some were more affected than others. Questions will also be raised about the support young carers have received and the effectiveness of pastoral care in places of education.

6.4.1 Impact of caring role upon education

Survey findings showed that there was little variation between those who agreed their caring role had impacted upon their education (41.4%) and those who disagreed (34.5%). There was however, a more marked difference in responses to two other statements regarding impact, over half of respondents (55.2%) disagreed that their caring role had had *little impact* on their education and just over a quarter (27.6%) agreed that their caring role had a *significant impact* on their education. These findings further highlight the complex nature of the circumstances of young carers. The literature also referenced young carers as experiencing varying degrees of impact on their education because of their caring role (Smyth et al., 2011). Whilst some young carers revealed their education was not overly impacted (Nagl-Cupal et al., 2014; Fives et al., 2013; Bjorgvinsdottir and Halldorsdottir, 2014; Eley, 2004; Banks et al., 2001), these contrasted the findings of Szafran et al., (2016), Kauvanagh (2014), Sieh et al., (2013), Diaz et al., (2007) and Thomas et al., (2003) where a negative association between caring and education was described. Two main explanations are posited as to why some young carers believed their education was more impacted on than others and both of these centre around the condition of their cared for person. Firstly, that impact was dependent on the condition of the person they were providing care to at that particular time (Smyth et al., 2011), and secondly, identified as particularly at risk were those young people caring for someone who misuses drugs or alcohol (Becker and Dearden, 2004). These links are comparative to what several

of the professional interviewees highlighted when discussing young carers receiving support from their families. While positives were mentioned, the adverse consequences of partial or no parental support were acknowledged; this included, for example, parents who, due to their condition, were unable to provide the encouragement needed to motivate their child and professionals believed this could have potential negative impact on a young carer's experience of education.

These findings indicate that more research is needed to ascertain the reason why young carers are reporting such mixed views and why some feel their education is impacted more than others? For example, is it dependent on their support network, the relation of the cared for person to the young carer or the cared for persons condition? Due to the small sample size of this research such comparisons in data could not be drawn; a less time bound study could potentially engage a larger sample size for such comparisons to take place that can be tested for statistical significance for young carers in Northern Ireland. This would have implications for how particular groups of young carers can be best supported; for example, should a young person caring for a parent be routinely identified as at greater risk of poorer educational experiences. In terms of remedial measures, one option may be to initiate early intervention via the parent's social worker in the first instance to begin the process of ensuring the necessary supports are in place for the young person.

6.4.2 Impact of caring role on grades received

The findings showed when participants were asked directly in the survey *Has your caring role impacted on the grades received*, a majority (68.7%) agreed, in comparison to a minority (18.8%) who said it had not. This view was reiterated by half of young carer interviewees and was also suggested by five of the professional interviewees. While there may have been little variation amongst those young carers agreeing and disagreeing that their education had been impacted by their caring role, a different story emerged when asked about the impact on their grades. The relationship between a caring role and impact on grades was also identified in the literature, including the Scottish Youth Parliament (2014), Sempik and Becker (2014b), Bray (2013), Aylward (2009),

Roberts et al (2009), Warren (2005), Rowntree (2000) and Dearden and Becker (2000). Most comparable with the findings of this research is the work of Sempik and Becker (2014b) who found that just over half (54.0%) of 77 young carers felt they would have achieved higher grades had it not been for their caring role. This research recommended several methods of addressing this impact in a school context. These included; embedding into school policies “a clear framework of support for young carers”; a named young carers lead; individual plans for each young carers that focus on addressing “any barriers to education”; and specialised careers advice that recognises skills developed through a caring role (Sempik and Becker, 2014b, p.4).

This finding adds yet another layer of complexity to young carers and their circumstances. It also raises the questions - why is it that young carers feel this way? How can there be such a disparity between the responses to both subjects? Does this highlight the significance young people attribute to their grades in general and or is it due to the emphasis on achievement by their places of education? It was observed by several young carers interviewed, namely that good grades and academic pathways were more of a priority for schools than pastoral care. This was also reinforced by several professionals who considered schools placed league tables and exam results above understanding and support to a young carer.

There is undoubtedly a belief amongst young carers that their grades are impacted by their caring role. This is an area both in need of further research to establish what targeted support can be given to young carers to help address the practicalities of their circumstances, for example providing support options around revision and coursework as well as signposting and applying for special circumstances when sitting formal exams such as GCSE, AS and A Level.

6.4.3 Other Impacts on education

Information gathered regarding the ways in which their caring role had impacted on education further emphasised the complex circumstances of being a young carer, not least since there is no standard experience

Survey findings showed little difference between the numbers of young carers agreeing that their caring role had impacted on their wider educational experience in this way and those that did not. These included areas such as the completion of homework (51.7% agreed this was a problem compared to 37.9% who did not), and in relation to decisions they had made about their future education (47.1% agreed that their caring role had impacted, compared to 32.4% who said that it had not). Other areas revealed a more marked difference in the numbers reporting that their education had been impacted in a certain way compared to those who had not. Areas such as whether they experienced tiredness at their place of education due to their caring role (62.1% agreed they did, whereas 31.0% disagreed that this was the case); whether they had problems concentrating at their place of education (58.6% agreed they had, whereas 31.0% disagreed); and whether they had to take time off from their place of education to provide care (58.6% agreed they did, 34.5% did not). Impacts such as bullying and in relation to not being able to afford course textbooks or lunch in their place of education received the largest variation in response, for example 21.4% agreed they had experienced bullying, 78.6% did not. These findings were reinforced in young carer interviews, with at least three out of six interviewees confirming that they had experienced homework difficulties, tiredness, bullying, concentration problems, non-attendance because of their caring role and that this had also impacted on the decisions they had made concerning their future education. These observations were reinforced by professionals who provided examples from young carers they had worked with.

These findings are confirmed by literature, which dealt extensively on how having a caring role can impact on a young person's education to varying degrees. Examples of impacts covered included young carers having trouble completing homework (Szafran et al., 2016; Scottish Youth Parliament, 2014), problems with concentration and tiredness (Bleakney, 2014; Fives et al., 2013), absence (Sempik and Becker, 2014a; Pufall et al., 2014), bullying (Cluver et al., 2012; McAndrew et al., 2012) and how it impacted upon decisions young carers make about their future in general and in relation to their education (Hamilton and Adamson, 2013; Heyman and Heyman, 2013).

The variation of experiences outlined by this finding reinforces the need for stakeholders to provide support to individual young carers adopted for their

specific circumstance, that a one size fits all approach, while it may be easier to implement and may reduce some impact on young carers education is not the most effective response for young carers.

6.4.3.1 Financial difficulties

Small numbers of young carers revealed they were unable to afford textbooks for their courses (7.1%), unable to afford lunch at their place of education (10.3%) or to take part in extra-curricular activities (10.3%). These examples of financial difficulties correspond with national and international literature (Evans and Becker, 2009; Moore et al., 2009; SCIE, 2005). Financial difficulties and hunger were also raised by Szafran et al., (2016) and Cluver et al., (2012). Young carers experiencing problems affording equipment and lunch at their place of education is significant for two main reasons. Firstly, a link was identified in the literature between poverty and poor academic achievement (Liegghio, 2015; Bray, 2013; Evans and Becker, 2009; SCIE, 2005). Secondly, research and policy on child poverty in Northern Ireland has reported not only a correlation between poverty and poor academic achievement (Burns et al., 2015; Montieth et al., 2013) but that those young people living with a parent with a physical disability or ill health were more likely to be living in severe or non-severe poverty compared to their peers (Child Poverty Alliance, 2014; Montieth et al., 2013; Montieth and McLaughlin, 2004). Consequently, even though only a small number of participants identified as experiencing financial difficulties, this is of significance and could be an indicator of a greater problem a young carer and their family may be facing requiring intervention and additional support to help a young person reach their academic potential.

6.4.3.2 Dropping out

Dropping out of education because of their caring role was only acknowledged by a small element of participants as something they had considered (24.0% of survey respondents and two interview participants) with interviewees

commenting that whilst they may have considered dropping out, they did not follow through. This finding varied from the literature when small numbers were recorded as actually dropping out because of their caring role and not just considering it as a potential option (Sempik and Becker, 2014a; Sempik and Becker, 2014b; Scottish Youth Parliament, 2014; Cluver et al., 2012; Cass et al., 2009; Finnerty and O'Connell, 2009; Zhang et al., 2009; Robson et al., 2006; Thomas et al., 2003; Lackey and Gates, 2001). A larger NI study may provide a more comparable insight. This finding could be indicative of the positive mindset and positive attitude towards education displayed by research participants and as such highlights the importance of supporting young carers to reduce the impact of their caring role upon their education, because they do not see dropping out as an option.

6.4.3.3 Lack of understanding and support

This research found that significant numbers of young carers did not agree that those educating them understood their caring role, that they did not feel they were supported by them and that they did not receive the support that they needed. Over half (55.2%) of young carers did not agree that those educating them understood their caring role and two interviewees highlighted that they had experienced this lack of understanding, this was a view also collaborated by eight of the professionals that were interviewed. Numerous examples were provided of how young carers had experienced a lack of understanding from educators. In relation to whether or not they felt supported by their educators/school, the survey results found that over half (62.1%) did not feel supported compared to a minority (10.3%) who did. This was echoed in terms of receiving the support they needed, 69.0% disagreed that this was the case compared to the 20.7% who believed that they had. Regarding support received, it should be noted though that a number of young carer interviewees and professionals emphasised the importance of and the positive impact of having at least one teacher who was supportive, empathetic and understanding to their situation

These findings are similar to the experiences of young carers outlined in the literature from Australia, Canada, Iceland, Ireland and GB where it was well

documented that young carers were experiencing a lack of understanding and support from their place of education (Szafran et al., 2016; Bjorgvinsdottir and Halldorsdottir, 2014; Hamilton and Adamson, 2013; Heyman and Heyman, 2013; Family Action, 2012; Barry et al., 2011; Smyth et al., 2011; Robotham et al., 2010; Cass et al., 2009; Children's Commissioner, 2009; Finnerty and O'Connell, 2009; Barnardo's, 2006; Morgan, 2006; Eley, 2004; Roche and Tucker, 2003; Thomas et al., 2003; Underdown, 2002; Watson, 1999).

The finding raises questions about the effectiveness of pastoral care systems and policies in place in schools. It implies that current policy on pastoral care in schools is not effective at supporting young carers or is not being implemented effectively. This raises questions as to what the origin of this failure is and whether this is an experience unique to young carers or whether other marginalised groups face similar circumstances. Under the Education and Libraries (NI) Order (2003) this finding suggests that schools are not fulfilling their duty of care towards young carers. This may be due to a lack of awareness amongst teachers about the identification, issues and needs of young carers or it could be, as suggested by some professionals in this study, that the workload of teachers precludes the expectation that they will identify and support every young person with a problem in school in addition to delivering the requirements of the curriculum. Irrespective, this finding highlights that attention needs to be given to how pastoral care systems/policies address the needs of all marginalised groups of young people and thought given to what is the most effective means of doing so.

6.4.3.4 How these findings compare to the findings of YLT on young carers and the impact of their caring role on their education

From the results of YLT 2010 and YLT 2015, a limited amount about young carers and education in Northern Ireland in relation to their experiences of missing school, attending out – of – school activities and the impact of their caring role on their schoolwork. When the results of this research were examined in relation to the findings of YLT 2010 and YLT 2015, both sets of findings presented contrasting results and the following observations were made.

The findings from this research and those from YLT differed significantly on whether young carers felt that their schoolwork had been affected or impacted upon by their caring role, whether they had missed school because of their caring role and whether this had also lead to them missing out on out- of- school activities . This research found that almost two-thirds (63.0%) of respondents agreed or somewhat agreed that their caring role had impacted on their grades with just under twenty percent (18.8%) disagreeing that this was the case. This contrasted with the two-thirds of young carer respondents in YLT 2010 who strongly agreed or agreed that their schoolwork had not been affected by their caring role. On the topic of missing school, a much greater number of respondents in this research (34.5%) indicated that they had missed school than was the case of YLT 2010 (9.0%) and YLT 2015 (12.0%). This research identified that almost as many young carers in NI reported that they were missing out on out – of – school activities (44.8%) as those who said they did not (51.7%). This contrasted with the average of just over three-quarters (79.0%) of respondents to YLT 2010 and YLT 2010, who said that their attendance at out- of-school activities had not been impacted upon by their caring role.

Regarding the types of support that young carers received, YLT2010 reported that only a minority of young carers (10.0%) said that teachers gave them support (YLT 2015 did not ask a similar question to compare results). Respondents to this research project identified that while they would say they had received support in relation to their education from their class teacher (37.1%) and/or from a pastoral care teacher (20.0%) over sixty percent (62.1%) felt supported by their educators and sixty-nine percent believed that they did not receive the support with their education that they needed. Over half of respondents felt that those educating them did not understand their caring role.

The differences between these results show that further research is needed on a larger scale into young carers in Northern Ireland. It should be noted that the YLT study and this study did use two different sampling methods. YLT results were based upon a random sample, whereas due to this being a timebound study a non-probability, purposive sample backed up by a snowball sampling strategy was used. This is of significance as this study engaged young carers who had been identified and where currently or had been receiving support from a young

carer organisation. There is potential that because those participating had been identified and referred to a young carers organisation they were more likely to be experiencing negative impacts linking to their caring role than those young carers identified through the random sampling strategy of YLT.

6.4.4 The experience of professionals building relationships with schools

A significant number of professionals in this study had experienced difficulties building relationship with places of education– with access to teachers the most recurrently raised problem - be this in relation to making contact for a particular young carer or as a means of gaining access to raise awareness about young carers. Two of the three young carers organisations in Northern Ireland are tendered to provide their service by the Northern Ireland Health and Social Care Board (NIHSCB). One of the functions these organisations are contracted to provide is to raise awareness about young carers and develop relationships with schools, however this seems to be one-sided, something driven by the young carers' organisation's and there needs to be more partnership/joined up working between not just young carers organisations and schools, but between NIHSCB, DE and EA. Places of education are vital avenues of potential through which to identify problems with young people that would otherwise go unnoticed, it therefore makes sense for partnership working and the utilisation of outside agencies and organisations to relieve the pressure of expectation from teachers.

Having difficulty building relationships with schools has not featured strongly in the literature, nor has the promotion of partnership working between schools and young carers organisations (Stamatopoulos, 2015; Family Action, 2012).

6.5 Young Carers and their macro-system

Policy, strategy and legislation in Northern Ireland relating to young carers as outlined in chapter two, highlighted several issues of importance. Firstly, that under The Children (Northern Ireland) Order (1995), a young carer could be classed as a child in need due to the impact their caring role could have on their health, social and educational development. Secondly, that NI has incorporated the 1992 UNCRC into its children and young people's strategies, this rights based approach includes every child's right to an education (Article 28) and that such an education must enable every child to develop their abilities to the full (Article 29). Both the Children (NI) Order (1991) and the UNCRC therefore should be the underpinning elements of all policy, strategy and legislation relating to young people in Northern Ireland.

Policy in Northern Ireland, while some has evolved and been more explicit than others in relation to young carers, this research has identified that for a significant number of young carers in Northern Ireland, their education experiences are not being supported to allow them to compete on par with their peers to offset the impact a caring role may have on their education, to enable them to fulfil their academic potential.

Most significantly however, Chapter Two of this thesis highlighted that within education policy, strategy and legislation in Northern Ireland, young carers are only explicitly named in one policy launched by the NI Executive and DEL, the 2012 Pathway to Success Strategy which aim was to ensure every young person by 2020 would have the opportunity to access education, training or employment. This was despite there being a practice of providing examples of groups of young people identified as target groups for other education policies. Carers policy, such as Valuing Carers: Proposals for a Strategy for Carers in NI (2002), 'Caring for Carers: Recognising, Valuing and Supporting the Caring Role' (2006) and the Review of the Support Provisions for Carers (2009), all made recommendations about the need for better joined up service delivery for example between DHSSPS, DE and DSD, which raises the question why then were young carers not specifically mentioned in education policy being formulated/introduced from this same time period? Additionally, how does this align with the 2015 Children's

Services Co-Operation Act (NI) which promotes co-operation between Department and Agencies to deliver services to improve the health and well-being of children and young people. Contained in this Act, one of the eight parameters of well-being were named explicitly as 'Learning and Achieving'.

The findings of this research and the outlining of Northern Ireland's policy, strategy and legislation relating to young people providing unpaid care highlighted gaps in official sources of support to young carers such as EWO's, Children's Services and Young Carers Organisations- areas which should be covered by the 2015 Children's Services Co-Operation Act (NI). The positive role EWO's have had with young carers was highlighted by professionals in this research, however they commented how in most cases an EWO's role was only until a young person turned 16 years old. The feeling was that for many young people this is a time of transition, with young carers having the additional worries of their caring role, and as such the age criteria of those eligible for support from EWO's should be extended to the age of eighteen. The 2015 Equality Commission for Northern Ireland's commissioned research on education inequalities, identified young carers as a group who experience disadvantage and face specific barriers to their education (Burns et al. 2015). A significant gap was reported in the support provided to young carers once they turned 18 and were no longer under the remit of children's services. When the three young carers organisations were recruited for this study, two were funded by the Northern Ireland Health and Social Care Board (NIHSCB), and the other was funded through grant making bodies and trusts. The two funded by the NIHSCB ceased working with young carers once they turned 18, whereas the other provided a service up to the age of 23 years old. This has since changed, in March 2020, a new Young Adult Carers Service was launched, to provide support to 18 to 25 year olds, covering all of Northern Ireland.

The findings showed that significant numbers of young carers (62.5%) and professionals believed that their caring role had impacted on the grades they had received. It was highlighted how young carers believed their education had been impacted by non-attendance, lateness, concentration problems, tiredness, problems completing homework's, bullying, stigma, relationship with peers and for a small number, financial difficulties. The impact their caring role had upon the decisions they made about their future education was also evidenced. This raises

the question why young carers are not acknowledged or named in education policies, strategy and legislation when they are experiencing problems and difficulties with their education. Looked after children, children with disabilities and others with special educational needs along with other groups are routinely named- why not young carers? This could be attributed to a range of interconnected reasons. Has limited research in Northern Ireland helped minimise the profile of young carers and facilitated a lack of awareness and knowledge about young carers and education? Are young carers in Northern Ireland routinely not recognised as such within society as a whole and as such a link is not routinely made that such a role could impact on a young person's education? Is reporting on young carers low compared to other groups? Regardless of reason this is an area that needs to be redressed via further research on the subject and the area of young carers and education being made a priority particularly by DE and EA for review and consultation with stakeholders, actively engaging with young carers regarding what is needed to be done to actively alleviate the impact of having a caring role has on a young person's education.

These findings have shown that significant numbers of young carers did not agree that their place of education understood their caring role (55.2%), that they did not feel supported by their place of education (62.1%) and that they did not believe that they had received the support that they needed (69.0%). This coupled with the findings on the experiences of professionals; the difficulties being outlined of making contact with teachers, lack of referrals from teachers, the belief that teachers do not have the time to identify and support every young person with a problem emphasises that this is an area that needs to be addressed by the Education Authority, in policy, strategy and legislation being formulated by DE and through teacher training. Ultimately, all schools under the Education Libraries (NI) Order (2003) have a duty of care to pastorally support every pupil, this is a legal obligation for schools to be held accountable on, however as this evidence suggests they need educated and given further support to do so. The 2016, Miss School: Miss Out Strategy (DE) encouraged schools to formulate their own policies and practices in relation to attendance. In addition, it recognised how attendance problems can also be explained by personal and environmental factors. This provides an opportunity for schools to examine and consider the reasons why their pupils are absent and use this as the basis upon which to

develop the relevant practical and pastoral policies for their school. This is an example of how schools can be proactive on the subject of young carers.

The General Teaching Council for Northern Ireland document *Teaching the Reflective Profession* (2011) outlines the code and guidelines on the “nature of teaching and the competencies that underpin it” in Northern Ireland, many of which are supported by education legislation (p.5) ⁷¹. The introduction of this document states that a teacher’s responsibility is founded on the understanding that they are pledged to excellence and “that they will promote the health and well-being of those in their care” (p.5). The following commitment is outlined that teachers will:

encourage growth and development; acknowledge and respect the uniqueness, individuality and specific needs of each pupil and thus provide appropriate learning experiences; and aim to motivate and inspire pupils with a view to helping each realise their potential (p.45)

It is also outlined that teachers are to be “reflective practitioners” who “contribute to the review and revision of policies and practices with a view to optimising the opportunities for pupils or addressing identified individual or institutional needs”(p.45). Listed in the section ‘Professional Values and Practice’ is that teachers need to have a competent knowledge and understanding of “the factors that promote and hinder effective learning, and be aware of the need to provide for the holistic development of the child” (p.13). It is outlined how such a value is to be developed by a teacher from their initial teacher training, induction, Early Professional Development to Continued Professional Development, teachers are expected to assume responsibility for their own ongoing professional development. At the level of teacher training, to demonstrate competency in this area what is required is that consideration is given to “the key aspects of emotional and behavioural difficulties; trauma, child abuse, bullying, discrimination, stereotyping, and pupil mobility or absence from school” (p.22).

⁷¹ https://gtcni.org.uk/cmsfiles/Resource365/Resources/Publications/The_Reflective_Profession.pdf consulted on 21/04/2020.

As can be seen from the information above, the expectations and responsibilities of teachers in relation to pastoral care towards pupils is explicit as is their role towards evaluating and contributing towards policies and practices to help those young people who may need specialised support. The findings of this research however have indicated that the reality and the practice of such values and practice are not having a significant contribution towards helping lessen the impact of a caring role upon a young person's education or making them feel supported in their places of education. This would suggest that attention must be given beginning with teacher training and on an ongoing basis to all teachers on the area of pastoral care and on the issues that affect young people with particular attention being given to the more specific issues that may be affecting them such as a caring role in addition to more general topics. Consideration should also be given as to why despite the clear outlining of such values and practices this has been the reality.

6.6 Conclusion

Using an adapted version of Bronfenbrenner's Ecological Model, this discussion chapter has focused on the micro, meso and macro systems regarding young carers and education. Emphasis was placed on the fluid, porous nature of both the model and experiences of young carers relating to the interplay between layers.

At the micro-level, it was stressed the extent to which providing a caring role was an individual experience for each young carer. The positive attitude they had towards education, their view of school as a break from their caring role and their mixed feelings regarding whether or not they wished their educators to know about their caring role was also discussed.

At the meso-level, the complex nature of both the situation and experience of young carers was highlighted, illustrating while some generalisations may be made, assumptions cannot. Research findings relating to the impact of a young people's caring role on their education and in relation to the support they received was comparative to the literature. Questions were raised at this level about the effectiveness of pastoral care in places of education.

The macro-level emphasised the absence of naming young carers in DE policy, strategy and legislation compared to that of other government departments. This produced questions as to why this was the case and a need was identified for the area of young carers and education to be made a priority for research, review and consultation for DE and EA. A discrepancy was also highlighted between what pastoral policies and codes and guidelines relating to teachers' responsibilities to recognise the holistic approach to young people in education and the reality of these young carers experiences.

The subsequent and final chapter will provide a summary of how the research questions have been addressed and the key findings, as well as setting out the implications and recommendations following this research as well as possible impacts.

7.0 Conclusion

7.1 Introduction

The aim of this research was to examine the educational impact of being a young carer aged 16 to 24 years old in Northern Ireland. Little is known about the lived experiences of young carers in Northern Ireland generally, and even less about the impact of a caring role upon their education. Prior to this research, knowledge about young carers in Northern Ireland has been limited to census figures, social survey data (the Young Life and Times Survey) and a report commissioned by the Patient Client Council in 2010. Even the existing quantitative data had not hitherto been collated in one place to enable any changes over time to be identified.

A review of the literature in Chapter Three identified that: little empirical evidence was available on young carers generally; it was not quantified or evidenced by statistical data there was limited information on young carers post-18 years old and little research existed on education beyond school environs; This research study was therefore designed to begin to address these while focusing on the research questions.

In order to gain a more detailed understanding, a mixed methods approach was adopted. Data was collected via survey and interview from young people with a caring role aged 16-24 years and via interview with professionals employed by young carers organisations. The research design focused on ascertaining the educational experiences of young carers, the relationship between their caring role and education, the support they received and how they can be supported to fulfil their educational potential.

7.2 Key findings

The research design enabled a richer understanding and insight of findings on the experience of young carers of education in Northern Ireland not previously examined.

7.2.1 Addressing the research questions

What are the educational experiences of young carers aged 16-24 in Northern Ireland?

The research findings emphasised both the commonality and the individuality of each young carer's experience illustrating both the common elements and the spectrum of situations young carers in Northern Ireland find themselves in both personally and educationally. Survey results and interview findings provided comprehensive details of the variations of caring roles respondents were performing, for example in relation to who they were providing care to, how often they were providing care, the health condition of the person they are providing care to, the types of care being provided and how long they had been carrying out their caring role. In relation to their educational experiences, findings highlighted how the levels of impact upon their education varied between young carers. Examples of this would be 7.1% of respondents revealing they were unable to afford the required text books for their courses compared to the 85.7% who disagreed they had this experience; 17.2% of respondents saying they experienced bullying because of their caring role and 78.6% saying they did not and 58.6% admitting they had concentration problems at school because of their caring role and 31.0% said this was not their experience.

The findings established that the majority of participants (65.5% and five out of six young carer interviewees) had a positive attitude towards their education, they wanted to succeed, and education was something of value to them. Linking to this, professionals identified a positive mindset as being key to motivating young carers to persevere with their education. A mindset that was defined as incorporating resilience, self-belief and self- confidence.

Almost three-quarters (69.0%) of survey respondents agreed that their place of education was somewhere that offered freedom and a break from providing care. In spite of this, both survey respondents and young carer interviewees revealed very mixed feelings on sharing their caring status with educators. Almost 40% of respondents (37.9%) both agreed and disagreed about whether they wanted to inform their place of education about their caring role, and when asked whether their educators were aware of their caring role 37.9% responded both ways.

Despite most respondents displaying a positive attitude towards their education and viewing their place of education as providing them with freedom from their caring role, it has to be acknowledged that 17.2% of respondents did not feel free from their caring role at school, 21.4% felt that their place of education added to their problems, 34.5% and 24.1% felt that their caring role contributed to them feeling lonely and isolated respectively at their place of education. Three young carer interviewees reported conflict between their education and their caring role and four were open about the fact that their caring role took priority over their education.

Additionally, almost two-thirds (62.5%) of respondents and three young carer interviewees believed that their caring role had impacted upon the grades they had received, 55.2% and two young carers interviewees agreed that their educators did not understand their caring role and 62.1% said that they did not feel supported by their educators and 69.0% disagreed that they received the support they needed from their educators. Four young carer interviewees admitted they either struggled to tell their teachers about their caring role or worried about their teachers' reaction to being told about this.

How has the caring role impacted on their experience of education and/or career prospects?

Over one third (41.4%) of participants agreed that their education had been impacted by their caring role and 62.5% agreed that their grades had been affected with half of young carer interviewees reporting that their caring role had conflicted with their education. Four out of six young carer interviewees disclosed that their caring role took priority over their education, with two of them outlining how doing so had consequences such as not getting enough sleep and having to cope with “*constant panic*” about their coursework (YCInt6).

When asked about the other ways in which their caring role had impacted on their education, the variety of ways in which young carers were experiencing this was highlighted. Overall, it was identified that participants were most likely to experience a combination of problems such as completing homework/coursework, with tiredness, with concentration, non-attendance and/or lateness at or to their place of education, unable to participate in extra-curricular activities, bullying and financial hardship. For example, just under half of participants (48.6%) reported having to take time off from their place of education 51.4% said they experienced tiredness at school because of their caring role. Interestingly, despite experiencing such impacts on their education, dropping out had only been considered by a minority and had not been acted upon (24.0% of survey respondents and two interview participants).

Almost half (47.1%) of survey respondents revealed that their caring role had impacted or somewhat impacted on the choices they had made about their future education choices. Survey respondents provided several examples as to how this has been the case for them: that their choice of university was linked to proximity to their home and cared for person; that their caring role had related to/impacted on their chosen career path and that they chose their course because they believed it would benefit their family financially in the long term.

Just under one-third of respondents agreed they felt that their career prospects had been impacted upon by their caring role and it was indicated by half of young carer interviewees that their caring role had directly influenced their choice of career.

Professionals identified several obstacles they believed young carers faced regarding their futures these included: making decisions regarding their future based on their caring role; having restricted options; the young person falsely believing that it is easiest for their caring situation if they stay at home; feeling hopeless about their future and feeling restricted by their perception of their caring role which may not be the reality.

What help did young carers received to support them with their education and how can they be supported to fulfil their educational potential?

This research identified that on the topic of help young carers received to support them in their education that: the majority of respondents identified that they did not feel understood or supported by their educators; young carer respondents did however report that they did have sources of support with their education and identified family as their main source of support; the role young carer organisations played in supporting young carers with their education and the positive and negative experiences of young carer professionals regarding building relationships with places of education.

Perhaps most significantly about support, over half of survey respondents (55.2%) agreed that their educators did not understand their caring role, 62.1% said that they did not feel supported by their educators and 69.0% disagreed that they received the support they needed from their educators. Young carer interviewees provided examples of situations when they had experienced a lack of understanding from teachers and teachers not responding in a sensitive manner when they had knowledge of the young person's caring responsibilities. Contrary to the more negative experiences young carer interviewees did also provide rich commentary on the support they had received with four interviewees outlining the significant positive impact having support from one or two specific teachers had been to them.

When asked explicitly via survey to identify who did provide them with support in relation to their education, family was the most reported source of support that they had (60.0%), followed by young carers organisations (54.3%), friends

(42.9%) and only then were class teachers (37.1%) and pastoral care teachers (20.0%) ranked. Such sources of support were also discussed by young carer interviewees with half of them referring to the role their family played in helping them manage the relationship between the caring role and their education. Contrasting with this though, five professionals described how family influence can have a negative impact on young carers, for example; in the sense that they feel guilty about leaving their cared for person; parents, perhaps due to their illness, being unable to provide the necessary motivation and encouragement that their young person needs; examples were given about young carers adopting a parent or cared for person's behavioural issues or traits and it was suggested that for some young carers they were susceptible to repeating family cycles or behaviours for example in relation to not pursuing higher education.

It was noted from the findings eight different ways recognised by young carer participants as to how young carers organisations had helped them with their education, these were: advice; a break from their caring role; facilitating the sharing of experiences with other young carers about how they coped with their education and caring role; helping a family out when experiencing financial difficulties, liaising with young carer's schools; providing general support and leaders being described as influencers to young carer's and providing them with someone to talk to.

The research highlighted that most young carer professionals interviewed (eleven out of the thirteen) reported having had a degree of positive interaction building relationships with schools. These positive experiences were classified into two categories: a teacher or school being proactive about young carers, for example establishing young carers groups, and professionals experiencing positive reactions when they advocated on behalf of young carers to their place of education. Despite these positive examples given by the professionals, many (eight out of the thirteen interviewees) also gave detailed examples of how they had experienced difficulties building relationships with schools, be it in relation to seeking access to raise awareness about young carers in general or making contact to organise specific support for a particular young carer.

The second part of this research question 'how can they be supported to fulfil their educational potential' will be addressed in Section 7.5 when

recommendations identified from the findings and reflective discussion will be outlined.

How does the educational experience of being a young carer in NI compare with GB and elsewhere?

In Chapter One it was explained how this research was influenced by the work of Becker and Becker (2008) and Sempik and Becker (2013a; 2013b) who had researched young carers aged 16 to 24 and their education in England, Scotland and Wales. It was also outlined how this was an area not previously focused on in Northern Ireland, and that this research was designed to address this knowledge gap.

When the findings of this research were compared to the work of Sempik and Becker (2014a; 2014b), Becker and Becker (2008) and the research of others, the majority were backed up and provided with insights and possible explanations for why such findings may have been made. The similarities between this study and pre-existing research carried out in the UK and elsewhere will now be outlined. (From the outset the work of Sempik and Becker (2014a; 2014b) provided a source of figures with which to compare these findings due to the limited quantitative information available on young carers and the impact of their caring role on their education).

Most survey respondents had a positive attitude towards their education, they are ambitious and wanted to succeed (65.5%). This same attitude was identified in the research from Australia and the United Kingdom which provided suggestions/explanations about the origins or contributing factors to such an attitude (Smyth et al., 2011; Cass et al., 2009; Evans and Becker, 2009; Eley, 2004; Thomas et al., 2003). Professionals also identified several young carers displaying a positive mindset, consisting of self-confidence, resilience, self-belief something that was also noted by studies over England, Scotland and Wales (Evans and Becker, 2009; Eley, 2004; Thomas et al., 2004). Also reinforced by the literature was the finding that over half of survey respondents said they felt free from their caring role while at their place of education that it gave them a

break from their caring role. Additionally, several young carers (17.1%) identified their place as education as adding to their problems for example because they do not feel supported or experiencing bullying (Szafran et al., 2016; Thomas et al., 2003).

Echoing what has been documented consistently in the literature this research found that over half of respondents (55.2%) and two interviewees said they did not feel that their educators understood their caring role, over half did not feel supported (62.1%) and 69.0% said that they did not receive the support that they needed. Sempik and Becker (2014a) commented that despite three-quarters of respondents reporting they informed their educators about their caring role, almost half (45.0%) said that they did not receive recognition as a carer or help from their place of education (p.3). Young carers in this study displayed mixed feelings about whether they wanted their educators to know about their caring role. Studies elsewhere in the UK provided insights as to why young carers in Northern Ireland may feel this way (Szafran and Duerksen, 2012; Barry et al., 2011; Robotham et al., 2010).

What is apparent throughout the research findings is that young carers in Northern Ireland are experiencing varying degrees of impact on their education because of their caring role. In particular, the research of Smyth et al (2011) (Australia) and Becker and Dearden (2004) (UK) provided explanations as to why some young carers are more impacted than others. The other ways in which young carers in this study reported their caring role was impacting upon their education, for example on their ability to complete homework, having problems concentrating and experiencing tiredness was also reinforced by studies from different parts of the world. The quantitative data collected by this study found over a third (34.5%) of survey respondents agreed that their education had been impacted by their caring role. This was less than the number of participants (56.0%) reporting experiencing difficulties with their education because of their caring role in the research of Sempik and Becker (2014a). On the subject of believing their grades had been affected by their caring role almost two-thirds (62.5%) of respondents in this research agreed that this was the case, a slightly higher number than the 54.0% of respondents reported by Sempik and Becker (2014b).

Only a small number of respondents in this study highlighted financial difficulties impacting on their education such as being unable to afford textbooks for courses (7.1%) or to take part in extra-curricular activities (10.3%). In light of the literature however this is of potential significance as an indicator of greater problems being experienced by young carers and their family as there is an identified link between poverty and poor academic achievement, this includes NI based research (Burns et al., 2015; Lieghhio, 2015; Bray, 2013; Montieth et al., 2013; Evans and Becker, 2008; SCIE, 2005). NI based research has also reported those living with a parent with a physical disability or ill health as more likely to be living in severe or non-severe poverty (Child Poverty Alliance, 2014; Montieth et al., 2013; Montieth and McLaughlin, 2004).

An area where this research differed from other findings was that while almost a quarter (24.0%) of survey respondents and two interviewees said that they had considered dropping out of education because of their caring role, they did not follow through, it was not seen as an option. This contrasts to studies from the UK, Australia, Ireland, China and Zimbabwe where young carers were identified as not just considering dropping out as an option but as actually dropping out (Sempik and Becker, 2014a; Sempik and Becker, 2014b; Scottish Youth Parliament, 2014; Cluver et al., 2012; Cass et al., 2009; Finnerty and O'Connell, 2009; Zhang et al., 2009; Robson et al., 2006; Thomas et al., 2003; Lackey and Gates, 2001).

Prior to this study, YLT 2010 and YLT 2015 provided the most detailed general information gathered about young carers in Northern Ireland to date which included a limited amount about the impact on their education focusing on their experiences about missing school, attending out- of-school activities and the impact of their caring role on their schoolwork. On the topics of young carers feeling that their caring role had impacted on their schoolwork, on them missing school and on their attendance to out – of – school activities, the finding of this research were significantly higher of those young people agreeing this was the case for them compared to YLT 2010 and YLT 2015. Due to the limited research available on young carers in Northern Ireland, this would suggest that further research is required on this subject.

7.3 Limitations of the study

Several limitations are identified in relation to the research. In presenting this research, the researcher has consistently sought to quantify findings. It is, however, acknowledged that, despite the best efforts of all three Northern Ireland Young Carers Organisations and the researcher, only a small sample was recruited (35 survey respondents, 6 young carer interviewees and 13 professionals). Due to the small sample size, tests for statistical significance and data comparisons could not take place. This research does not claim to be representative of all young carers in Northern Ireland; rather it provides an exploratory insight into the experiences of this group which could provide a basis on which to plan future research.

When the research approach was initially formulated, it was designed to include data from young carers post 18 years old, including those attending other educational establishments apart from schools. However, within the sample just over half of survey participants and 3 of the young carers interviewed were aged 18 and over. This was despite the best efforts of the researcher and supportive staff in the three young carers organisations to recruit young carers participants. This research used a non-probability purposive and snowball sampling technique, this was due to the sensitive and hidden nature of caring and the corresponding difficulties in identifying and accessing participants documented by other researchers'. Such a sampling technique does not allow for a sample to be recruited with a balance of ages represented. These respondents did provide an example of young people managing to continue their education to university level regardless of their caring role but offered little detail on the experiences of young carers in a place of education that was not a school.

Females were the predominant gender participating in this research, due to the small sample size the claim cannot be made that there is a link between gender and the impact of a caring role in Northern Ireland, only perhaps that for this study females were more likely to volunteer to participate than males. Ideally a more gender balanced sample would have been preferred.

7.4 Impact statement

Outside the academic community, it is envisaged that these findings will be of benefit in NI to young carers, young carers organisations, teaching professionals, Universities providing teacher training, the EA, the Department of Education (DE), the Health and Social Care Board (HSCB), Northern Ireland Commissioner for Children (NICCY), and the Department of Health, Social Services and Public Safety (DHSSPS). This is not a definitive list, it has been considered that as knowledge transfer/exchange occurs the research findings and recommendations may be disseminated to professionals, organisations, government departments where it was not originally anticipated. The researcher intends to circulate the key findings and recommendations of this research to young carers (via young carers organisations), young carers organisations, the EA, DE, HSCB, NICCY and DHSSPS.

It is the researcher's hope that this research will ultimately contribute towards an increased quality of life for young carers aged 16 to 24 in NI by improving their education experience through the addressing of the issues raised in this research. It is hoped that through doing so may also improve young carers' health and the levels of understanding and sensitivity they receive from their peers and society. It is also expected that these research findings will be utilised by young carers organisations, to lobby government, to inform their practice and train staff, provide NI specific information for awareness training and as evidence for funding applications for projects and or resources to support young carers with their education.

At a policy level, it is envisaged that this research will inform policy makers, especially education policy makers about the impact of a young person's caring role. It is hoped that attention will be paid to this research highlighting the need to explicitly name young carers in policy and that it will encourage a review of existing pastoral care policies and strategies.

What this research has shown is that within this hard to reach group, there is a diversity of experience but a need for support, particularly from within the education sector and system. The young people that participated in this research were all accessed through support agencies that work with young carers. Clearly

there are those that are not currently benefitting from such support. More needs to be done to reach out to and meet the needs of all young carers so that they can reach their potential, envision a positive future and work towards achieving their own life goals.

The original contribution that this research has made is that it provides additional information and new insights to the limited amount of knowledge known about young carers aged 16 to 24 years old in Northern Ireland, specifically in regards to the impact of their caring role and their education. It has also provided secondary analysis of the cross-sectional data available on young carers in Northern Ireland through the aggregation and collation of Census figures and the Young Life and Times Surveys.

7.5 Recommendations for policy and practice

This research was not intended to develop interventions to support young carers with their education, however the combination of findings and reflective discussion have led to a number of recommendations that can be made for policy and practice to support young carers with their education, many of which are interrelated. Young carers participating in the research also identified recommendations that they would give to other young carers and these will be outlined first before recommendations for policy and practice.

7.5.1 Recommendations to young carers from young carers

Poignantly, several young carer interview participants volunteered recommendations they would make to other young carers. These were as follows:

1. It is better to inform your place of education about your caring role.

“I’m going to be such a hypocrite here, tell the school” (YCInt2).

2. **Try to have things (friends and time to yourself) of meaning and interest outside of your caring role.**

“...try not to focus every ounce of your energy on to your caring role because you are young and have a life and deserve to...you deserve to shine” (YCInt3).

3. **Find a key person and/or place you can go to for support, guidance and use them as often as necessary.**

“...just having an outlet where you can go to just talk, is a big support” (YCInt4).

7.5.2 Recommendations for education policy

The findings raised questions about; the effectiveness of pastoral care systems and policies in places of education and the alignment of DE policies with the 2015 Children’s Services Co-Operation Act (NI). They identified that young carers are rarely explicitly named in education policy; gaps in the provision of official sources of support to young carers; young carers experiencing a lack of support and understanding from their teachers and a need to promote both informal and formal pathways of education. As a result, this research has identified the following recommendations for education policy.

1. **Young carers need to be actively and meaningfully involved in the formulation of policy and best practice guidelines to support them in education, reflecting findings elsewhere** (McAndrew et al., 2012; Aldridge, 2008; Warren, 2007). This could be addressed immediately through partnership working with young carers organisations to recruit young carers to consult with on the formulation of future policy and practice and as a means of evaluating current policy and practice.
2. **Young carers should be explicitly identified as a group in education policies, such as the Extended Schools Programme (DE, 2006), thereby recognising their need for additional support to reach their academic potential.** Certain groups of young people, for example looked after children and children with disabilities, are frequently listed within

policies as needing particular attention due to being at risk of having their education negatively impacted upon. These findings have shown that almost two-thirds of participants believed their grades had been affected by their caring roles and that they believed that their education had been impacted in numerous ways relating to their caring role. This highlights that young carers should be recognised as another such group and should be explicitly named within policy documents.

3. **Current pastoral care policies and legislation need to be evaluated to ensure their effectiveness.** This research found that significant numbers of young carers reported not feeling understood or supported by their educators, or that they had received the support that they needed- implying that current pastoral care policies and legislation are ineffective. It is therefore important that the origins of why this is the case be established and addressed. In addition, greater consideration of how DE policy aligns with the 2015 Children's Services Co-Operation Act (NI) is necessary to ensure joint working with other government departments (including health and social care) and relevant agencies.
4. **Attention needs to be given to the official areas of young carers support where gaps in provision have been highlighted for those young people aged 16 and over.** Areas that require immediate and long term attention include the age remit of Education Welfare Officers and providing age appropriate support for young carers who are too old for Children's Services and Young Carers Organisations but may find themselves much younger than other attendees at Trust Carers Groups.
5. **The promotion of informal education opportunities needs to happen alongside traditional education pathways.** An example of such opportunities could come through The Princes Trust, OCN's, and employability schemes. Long term this should help alleviate pressure off those young carers who experience difficulties fulfilling what is required with more traditional educational routes while still providing them with qualifications and job skills. This reflects findings from other studies

(Heyman and Heyman, 2013; Finnerty and O'Connell, 2009; Moore and Morrow, 2007).

6. Teacher training needs to be more specific and ongoing regarding issues affecting young people, especially those of young carers, highlighting the importance of sensitivity

A means by which this could be addressed both short and long term could be through the promotion and development of partnership between places of education and specialised voluntary organisations/charities

7.5.3 Recommendations for practice

7.5.3.1 Young carers organisations

Findings highlighted the complexity, similarities and uniqueness of each young carer's situation. They identified that young carers organisations want to work in partnership with schools but are experiencing difficulties accessing and building relationships them, and that there is a need for specialised careers advice. This research, therefore, would make the following recommendations for practice to young carers organisations.

- **There is a clear need for sustained partnership with schools to provide specialist support and help raise awareness about young carers.** Long term such partnerships could address the issues raised in this research of young carers experiencing a lack of understanding and support at their places of education; young carer professionals experiencing difficulties making contact with and building relationships with places of education and the pressure teachers are facing balancing curriculum delivery and addressing the pastoral care needs of young carers.
- **There is scope to explore the possibility of offering specialist careers advice for young carers.** Young carers professionals involved in this research outlined components of what a successful specialist careers

advice for young carers would look like. This included: the foundation of all advice being exercising understanding and sensitivity towards the young person's caring role; educating young carers about their options and rights; highlighting options outside of a caring role; teaching young carers to identify and utilise the skills they have learnt through their caring role to complete job applications and/or applications for further or higher education.

7.5.3.2 Recommendations regarding practice for educators and places of education towards young carers.

The recommendations for practice for educators and places of education are founded on the research finding that significant numbers of young carer participants identified that they did not feel understood (55.2%), supported (69.0%) or that they received the support they needed (69.0%). This finding emphasised the need for places of education to increase their awareness and ways of supporting young carers; for educators to be trained about young carers; the benefits of utilising outside organisations to support pastoral care and raise awareness; and the promotion of a safe nurturing environment.

- **Places of education should make use of the specialist resource 'Supporting Young Carers in School: An introduction for Primary and Secondary School Staff' (HSCB, 2017).** Making use of this resource has the immediate benefit that educators have a valuable one stop document that can immediately give them information on the situation's young carers face and how they can support them. The goal of long term use should be an adoption or formulation by individual places of education of a Young Carer Specific Policy that is proactive in identifying and supporting young carers, and based upon the examples of good practice and frameworks contained within this resource.
- **It would be beneficial for Educators and places of education to utilise outside organisations such as charities to support their pastoral care strategies and staff.** A number of Young Carer Professionals highlighted during this research the belief that educators /places of education were under pressure with their workload of covering curriculums and do not

have time “to identify everything with every young person in the school” (P5). Collaborative partnerships with young carers organisations could help alleviate pressure off educators and facilitate better identification and support of young carers. They could also help with raising awareness about young carers to pupils and staff and to promote knowledge and understanding (Stamatopoulos, 2015; Szafran and Duerksen, 2012; Moore and Morrow, 2007).

- **Educators need to be educated, equipped and supported to help those identified as young carers.** Training should ongoing and promote understanding and sensitivity in responding to young carers and provide advice on providing specialised careers advice (Family Action, 2012; Hill and Thomson, 2009; Barnardo's, 2006). This recommendation could be fulfilled via the implementation of the previous recommendation outlined which promoted collaborative working with young carers organisations.
- **Places of education need to create and promote an environment where talking about problems and feelings is encouraged and young people have a means of accessing pastoral support discreetly.** Both this empirical research and a review of the literature highlighted the positive attitude young carers are displaying towards their education, their resilience to not choose dropping out as an option and how for some going to their place of education is viewed by them as a break from their caring role. One means of immediately addressing this recommendation could be addressing in assembly issues that young people may face with a view to educate and reduce stigma. Each pupil could also be provided with information signposting them on how to access pastoral support in their place of education. Section 7.5.3.3 provides recommendations of additional practical ways young carers can be helped within their places of education that could help foster the feeling of a safe and discreet environment for young carers to identify themselves in and seek support.

7.5.3.3 Recommendations for practical ways educators could help young carers within education.

The young carers and professionals participating in this research identified several practical ways educators could help young carers in their places of education. They were as follows;

- An identified member of staff who young carers know to approach for pastoral help and support (McAndrew et al., 2012; Robotham et al., 2010; Cass et al. 2009; Moore and Morrow, 2007; Warren, 2007; Barnardo's, 2006; Underdown, 2002; Watson, 1999).
- Enabling young carers to have access to a telephone while at their place of education (Cass et al., 2009; Underdown, 2002).
- Providing a visible indicator, (such as a card), that could be shown to a teacher to discreetly make them aware that a young person is a young carer, so the pupil does not have to explain.
- Permit extra access to computers if required.
- Exercise flexibility towards young carers and their education. For example around homework or coursework completion (McAndrew et al., 2012; Waugh, 2012; Smyth et al., 2011; Robotham et al., 2010; Alyward, 2009; Cass et al., 2009; Hill and Thomson, 2009; Roberts et al., 2008; Warren, 2007; Morgan, 2006; Moore, 2005).
- Help young carers apply for special consideration/circumstances (if required) when sitting GCSE's, AS and A Levels (Fives et al., 2013).
- Use the option of 'excused absences' for those young carers missing school because of their caring role to protect young carers EMA.
- Provide study opportunities for pupils either during school or after school (Waugh, 2012; Warren, 2007; Underdown, 2002).
- A focal point (such as a notice board) within places of education advertising support services available.
- The provision of peer to peer support groups.
- The use of a worry box where pupils can write a brief description of what is concerning them, and a teacher or support services worker

could talk to them about it and organise/provide any necessary support.

7.5.3.4 Recommendation for practice for the Education Authority, Department of Education and other Government Departments

1. There is a need for consistent recognition at Department and EA level to be given to young carers as a group of young people who have their education impacted upon by their caring role; and as such require effective pastoral care policies and support to help them fulfil their educational potential.

A review of legislation, policy and strategy of education policy identified that young carers are hardly ever explicitly named in policy, gaps were highlighted in the provision of official sources of support for young carers and questions raised about joined up service delivery.

In order for this recommendation to be met long term young carers need to be made a priority for research, review and consultation for DE and EA and to be recognised as a group that educators require specific training on. Policies relating to pastoral care in schools also need to be actively promoted and evaluated for effectiveness with a view to updating as required (Bjorgvinsdottir and Halldorsdottir, 2014; Hill et al., 2011).

As an immediate action the resource 'Supporting Young Carers in School: An introduction for Primary and Secondary School Staff' (HSCB, 2017) should be made a point of reference for the Education Authority, Department of Education and other Government Departments and circulated for use amongst the Primary and Secondary education sectors. Places of education should also be encouraged to make contact with and utilise outside specialist organisations such as charities to support their pastoral care strategies and staff (Stamatopoulos, 2015; Moore and Morrow, 2007).

7. 6 Recommendations for future research

Empirical evidence on young carers remains limited in Northern Ireland. This research does not claim to be a definitive study on young carers and education in Northern Ireland, but it does provide hitherto unexplored insight into the educational experiences of young carers aged 16-24, in particular, the impact of caring on their education and the implications of this for their current prospects and future choices. These insights therefore provide a fresh lens from which to plan future research.

Firstly, young carers were recognised in this study as having a positive mindset towards their education which merits further investigation. In exploring this, potential factors to consider are the qualities of individual young carers, the support and encouragement they receive at school and/or home or a combination of these. Additionally, does possessing one of more of these increase a young carers resilience and coping ability?

Secondly, why do some young carers report that their education is impacted more than others? This research revealed that many young carers agreed that their grades had been impacted upon by their caring role, why and how is this the case?

Thirdly, research would be helpful on the role of pastoral care in schools to support disadvantaged groups. It is suggested that this includes an examination of the expectations and responsibilities of teachers in relation to pastoral care, and an evaluation regarding whether this is realistic alongside the delivery of curriculum.

As mentioned earlier in this chapter, a review of the literature as outlined in Chapter Three, identified areas that have been given limited coverage in other research. This research was designed to gather information to address these areas. It would be recommended that future studies of young carers in Northern Ireland also seek to incorporate addressing these elements within their research methods. These areas consist of:

1. Little empirical evidence- research not backed up by statistics.

2. Limited information on young carers post 18 years old or studying in other places of education than schools.
3. Whether there is the same link between gender and a caring role that was identified in the rest of GB in Northern Ireland.

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Appendix One - Journal article on systematic review undertaken

Statement of Contributions of Joint Authorship

Campbell, A., Taylor, B., Bates, J. and O'Connor-Bones, U. (2018) Developing and applying a protocol for a systematic review in the social sciences. *New Review of Academic Librarianship*, 24 (1), 1-22.

Allison Campbell (Candidate)

Writing and compilation of the manuscript, conducting the systematic literature search on which the article is based – defining concept groups and search terms, testing and refining search formulas, calculating the sensitivity and precision of search findings and sorting the findings by relevance.

Dr Brian Taylor, Dr Jessica Bates and Dr Una O'Connor Bones (Co-Authors)

Editing of manuscript and inserting additional literature for the article. Guidance on search strategy and recommendations regarding which databases to include in the search strategy.

New Review of Academic Librarianship

Developing and applying a protocol for a systematic review in the social sciences

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Abstract

The paper reports on a systematic method of undertaking a literature search on the educational impact of being a young carer (16-24 years old). The search methodology applied and described here in detail will be of value to academic librarians and to other education researchers who undertake systematic literature searches. Seven bibliographic databases and Google Scholar were searched between November 2015 and January 2016. Two and three concept search structures were compared, involving 28 search terms plus truncation variants. One hundred and eighty one relevant articles were retrieved. Sensitivity, precision and 'unique articles retrieved' were used as metrics. Social Care Online and Google Scholar had the greatest sensitivity. As well as meticulous use of AND, OR and bracket operators, the use of NEAR and NOT operators to increase precision were tested and are recommended as useful tools for conducting systematic searches.

Keywords

Academic librarians, literature search, bibliographic database, Google Scholar, education, young carer

Introduction

Systematically searching databases in the social sciences has not been given extensive examination in the literature (Best et al., 2014, p.348). It has been suggested that its multi-disciplinary nature, the lack of agreed terminology and the range of research methods used, makes database searching in the social sciences intricate (McFadden et al., 2012; Taylor et al., 2003). While the use of systematic reviews in education research is certainly not commonplace, Evans and Benefield (2001, p.39), in their examination of whether the 'medical model' of systematic reviews could be applied to education research, concluded that the success and value of systematic reviews for education research would depend on the question that was being addressed and that "Firstly ... such reviews should be given the status and time allocation of a significant research project... Secondly, the review should

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focus on a specific question, and have clearly defined criteria for including and excluding studies. The advice of an expert panel is useful for helping to clarify the scope of a review. Thirdly, it is important to have clear criteria for assessing the methodological quality of the studies in order to evaluate their 'soundness' and the weight which can be given to their findings." Systematic reviews in education research include McGrath and Van Bergen (2015); Mager and Nowak (2012); O'Brien (2009); Rix et al. (2009); and Nind and Wearmouth (2006). Furthermore, staff in the EPPI-Centre¹, based at the University College London Institute of Education, UK have carried out systematic reviews on a range of education topics and questions.

The purpose of this paper is to document how a systematic literature search can be adopted in educational research. It also highlights how such a method of searching is of transferrable value to other social science disciplines. It is intended to be of use by academic librarians who contribute to the literature search process. Increasingly academic librarians have an 'embedded' role within the research process (Delaney and Bates, 2015).

The search topic for this study is: the educational impact of being a young carer aged 16-24. A young carer is a child or young person under the age of 24, whose life is affected by providing significant care, assistance or support to sick or disabled relative at home, with the term young adult carer specifically used for those aged 18-24². Research carried out by Becker and Becker (2008) and Sempik and Becker (2014; 2013) on young carers in the United Kingdom (UK) has reported that having a caring role can impact on a young person's education and subsequently on their career options and future economic potential. Findings have suggested that young people may not be in work due to their level of educational qualifications which could also be potentially coupled with the assumption that they will continue with their caring role (Sempik and Becker, 2014). Sempik and Becker reported that the highest GCSE grades held by the young adult carers they surveyed were most commonly at grade D-G (Sempik and Becker, 2014). Such information reinforced the views of young carers in earlier research, who felt they had left school with qualifications not of the standard that they were capable of achieving due to their caring role (Becker and Becker, 2008, p.33). These findings highlight the need for further research into the educational impact of being a young carer.

In order to carry out a systematic review of the literature on the educational consequences of being a young carer, a systemic literature search was first undertaken and it is the methodology of this search that is being reported here. In accordance with PRISMA-P guidelines (Preferred reporting items for systematic review and meta-analysis protocols), the systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO)³ on 1 May 2016 (registration number

¹ <http://epi.ioe.ac.uk/cms/>

² For definitions of young carers and young adult carers see: Sempik and Becker (2014); Sempik and Becker (2013); Becker and Becker (2008); Northern Ireland Department of Health, Social Services and Public Safety (2006); and Dearden and Becker (2000).

³ <http://www.crd.york.ac.uk/prosperto/prosperto.asp>

CRD42016037990).

Selection of databases

For this literature search, seven bibliographic databases were used as well as the web search engine Google Scholar. Similar studies have compared the effectiveness of using different databases for systematic searches in other disciplines for example, health care (e.g. Brett and Long, 2001; McNally and Alborz, 2004). However as they pre-date Google Scholar there is no discussion of the effectiveness of this or other search engines for academic searching in these papers. Details of the databases are provided in Table 1 below. These databases were chosen based on systematic review guidelines from The Social Care Institute for Excellence (SCIE) (Rutter et al., 2010); the experiences of other researchers (McGinn et al., 2016; Best et al., 2014; McFadden et al., 2012; Papaioannou et al., 2010; Taylor et al., 2007; Taylor et al., 2003), consultation with subject librarians; scoping exercises for relevant literature and on accessibility within Ulster University where the work was undertaken. Due to the nature of the topic, it was advisable to include databases from both education and from social care (social services), as well as a multidisciplinary database, which was SCOPUS. PsycINFO was included because of its focus on behavioural and social science research.

Table 1: List of databases

Database	Background
ASSIA (Platform: ProQuest)	ASSIA (Applied Social Services Index and Abstracts) is an international database, containing around 400,000 records from 500 peer-reviewed journals covering social services, health and psychology.
BEI (Platform: EBSCO Host)	BEI (British Education Index) has more than 230,000 articles indexed covering all areas of education in the UK.
ERIC (Platform: ProQuest)	ERIC (Education Resource Information Centre) is an international database containing over 1.5 million education related publications and resources.
PsycINFO (Platform: OVID)	PsycINFO is an international database containing over 3 million records from 2,500 peer reviewed journals.
SCO	SCO (Social Care Online) is a UK database containing over 155,000 records formed by the Social Care Institute for Excellence covering all areas of social work and social care.
Scopus (Platform: Elsevier)	Scopus is an international, multidisciplinary database consisting of over 49 million records from over 20,000 peer reviewed journals.
SSA (Platform: ProQuest)	SSA (Social Services Abstracts) indexes articles from over 1,300 peer reviewed journals concerning social work, human services, social welfare, social policy and community development.
Google Scholar	Google Scholar is a web search engine focused specifically on scholarly content. It crosses academic fields and covers an estimated 100 million English language documents (Khasba and Giles, 2014).

In addition to identifying the databases, it is important to also specify the platform, or database provider, as has been done in Table 1 above. In Campbell⁴ Systematic Reviews,

⁴ "The Campbell Collaboration (C2) helps people make well-informed decisions by preparing, maintaining and disseminating systematic reviews in education, crime and justice, and social

Hammerstrøm et al. (2010, p33) explain: "The same database is supplied by different organizations, called database suppliers ... Each database supplier produces their own search software and packages the data within the database differently (e.g. some fields may be included, others may not)."

Inclusion and exclusion criteria

For results to be included in the systematic review, articles returned by database searches needed to cover 'young carers aged 16-24' and 'education'. Literature on 'foster care', 'children in care' and 'looked after children' were excluded. All searches were limited to English language documents only, due to translation costs.

Sensitivity and precision

Database sensitivity (also referred to as recall) is defined as a measure of how many relevant articles are returned by a search divided by the number of known relevant studies on the topic (Best et al., 2014; McFadden et al., 2012; Taylor et al., 2007; Taylor et al., 2003). For the purposes of this study the number of 'known relevant studies' was the total number of relevant articles retrieved across all seven databases and the web search engine Google Scholar (Best et al., 2014). Precision is defined as the number of relevant articles returned by the search of an individual database divided by the total number of results retrieved for that specific database (McFadden et al., 2012, p.628).

$$\text{Sensitivity \%} = \frac{\text{no. of relevant results in one database}}{\text{total no. of relevant results across all databases}} \times 100$$

$$\text{Precision \%} = \frac{\text{no. of relevant results in one database}}{\text{total no. of results for that database}} \times 100$$

Sensitivity and precision have been described as having "an inverse relationship whereby, when sensitivity increases, precision decreases" (Best et al., 2014, p.351) Cochrane and Campbell Reviews seek maximum sensitivity and ignore precision to ensure that all relevant documents are retrieved for analysis, for example, in the cases of Langford et al. (2014), and Farrington and Ttofi (2009).

Retrieving irrelevant hits in the quest to locate relevant items is to be expected; however, to make results more manageable sensitivity needs to be counteracted by measures to ensure precision (Taylor et al., 2015). Adding more terms to a search may increase sensitivity but can also lead to more irrelevant results being returned (Taylor et al., 2003). It has been suggested that the key to developing a search formula is achieving a balance between sensitivity and precision – retrieving all relevant results and minimising any unwanted items (Lefebvre et al., 2011; Taylor et al., 2007). In order to increase the precision of a search and

welfare." (http://www.campbellcollaboration.org/c2_systematic_reviews/) They also provide resources and guidance on preparing systematic reviews.

make results more manageable, Taylor et al., (2003) suggest techniques can be used such as:

1. excluding studies (where able) for example in relation to this study articles covering 'children in care/looked after children' and 'foster care' were excluded.
2. using a proximity operator – in relation to this study this could mean including advanced text searching such as 'young NEAR/3 carer*' which retrieves articles where the word 'carer*' appears within three words of the word 'young'.
3. "qualifying or excluding words with many varied applications" for example the word 'care*' on its own due to the potential of returning many irrelevant results if used "without qualifiers" (Taylor et al., 2003, p.5).

Attention should also be given to the use of the Boolean NOT operator during the development of search formulas as a means of testing the addition of concept terms (Taylor et al., 2015; Best et al., 2014).

All of these techniques were considered throughout the formulation of a final search strategy and are discussed below.

Establishing concept groups and the selection of search terms

Overview

Sensitivity and precision were considered throughout the identification of concept groups while the task of converting the research topic into key search concepts was developed using the work of Best et al., (2014) and Taylor et al., (2003) for guidance.

Two concept groups

Originally two concept groups were identified – 'young carers' and 'educational impact'. The terms selected to express these two concepts were:

- "young carer*" OR "young adult carer*" OR "child carer*" OR "child care-giver*" OR "young care-giver*" OR "child caregiver*" OR "young caregiver*" OR "juvenile carer*" OR "children with dependant*" OR "young adults with dependent*" OR "young informal care giver"

AND

- Education OR school OR university OR exams OR employment OR NEET* OR "not in education" OR transition OR "educational impact" OR "academic achievement" OR "caregiver burden" OR unemployment OR achievement OR "educational inequality" OR "educational opportunities" OR training OR learning

Scoping exercises of journal articles and books found a variety of terms that expressed the concept 'young carer' and these were included in the terms outlined above. The range of terms "reflects the inconsistency of the way these terms are used in the literature" (Sprung

and Laing, 2015, p.4). It was acknowledged at this early stage that the inclusion of the terms, 'children with dependents' and 'young adults with dependents', had potential to affect the precision of search results as these terms are also used to describe young people who are parents. (Other research has also found this to be an issue, see for example: Fives et al., (2010). The group of terms selected to express the primary concept 'educational impact' sought to include general words relating to education and stages of transition in a young person's life during the ages of 16-24.

Testing of initial concept groups

Initially, these concepts were tested using text-term searching during scoping exercises on SSA (Social Services Abstracts) ASSIA (Applied Social Services Index and Abstracts) BEI (British Education Index) and ERIC (Education Resource Information Centre).

Quotation marks were used to focus the search on particular phrases, for example, "young carer" and truncation (*) was used to search for variants of words – mainly plural terms. (The search plan devised and used can be found in Appendix A).

Boolean operators, in the form of AND, OR, and NOT were used to "specify how the search terms are to be treated" (Taylor et al., 2015). For example, the Boolean operator AND was used to link the primary concepts and terms used to express each concept were linked by OR within brackets, in order to treat them as one "meaningful entity" (Taylor et al., 2015, p.55). The Boolean operator NOT was used to check the impact of new terms being added to the search formula. Taylor et al., (2015) explain the use of this operator in the following algebraic formula:

"(A OR B OR C) NOT (A OR B) ...to test for the impact of adding term 'C' to an existing search involving 'A OR B'"

Should the results of this formula not retrieve any results then the addition of 'C' to the equation can be deemed unnecessary and term 'C' does not need to be included in the search formula. This check was applied to each of the terms added to the search formulas in each of the four databases included in this scoping exercise. (An example of how the NOT operator was applied during these initial exercises can be found in Appendix B).

Table 2: Details of scoping exercise results

Database	Date of Search	Final Tested Formula	Total Retrieved	Hits	Number of Relevant Hits	Precision (%)
ASSIA	09/11/2015	("young carer*" OR "young caregiver*" OR "child carer*") AND (education OR school OR university OR employment OR training OR learning)	42		30	71.4

SSA	06/11/2015	("young carer*" AND (education OR school OR university OR "caregiver burden"))	32	15	46.9
BEI	11/11/2015	("young carer*" OR "young adult carer*" AND (education OR school OR university))	10	9	90.0
ERIC	12/11/2015	("young carer*" OR "child carer*" OR "young caregiver*" AND education)	36	19	47.2

Table 2 outlines the results of this initial scoping exercise. All results (minus two in the ERIC search which were on child care) contained information about young carers. However, all articles retrieved did not have a reference to both young carers and education. Frequently, subject identifiers and keywords were not explicit in regards to the literature covering the two concepts, in many cases although the concept "young carer*" was highlighted, references to education were vague.

This was a useful exercise as it helped identify key terms and database index terms relevant to the research topic and it also presented the opportunity to test search terms as they were added to the formula in a systematic way. As a result of this exercise, the list of terms to express the concept groups of 'young carer' and 'educational impact' were refined to the following:

- "young carer*" OR "young care giver*" OR "child carer*" OR "young adult carer*" OR "young caregiver"

AND

- Education OR school OR university OR employment OR training OR learning

This amended list reflects the terms tested as producing relevant hits during the course of the scoping exercise.

The searches carried out using two concepts were very focused and specific and as a result they produced small numbers of 'total hits'. However there was a concern that although using two concepts may give a high level of precision, there was not a high enough level of sensitivity to the search in order to ensure that it was comprehensive and that no relevant material was missed (McFadden et al., 2012).

Three concept groups

Using the revised terms for the two original concept groups of 'young carers' and 'educational impact' as a springboard, three concept groups were formed. The three concept groups formed were:

1. Care* OR Carer* OR caregiver* OR care-giver* OR care giver AND
2. Education* OR college* OR school* OR universit* OR training OR learning OR academic achievement OR academic attainment OR academic failure OR academic underachiev* OR academic aptitude AND
3. Child* OR children OR Adolescen* OR juvenile* OR young adult* OR young people OR teenager*

Systematic reviews published by The Cochrane Library and subject librarians were consulted to explore search terms for inclusion in the three concept groups (Eccleston et al., 2015; Blaxi et al., 2014; Lins et al., 2014; Legg et al., 2011; Vernooij-Dassen et al., 2011). At this stage it was decided that the term 'employment' would no longer be included in search terms as it was not an educational term. 'Exams' or 'grades' were not included as specific search terms as these were covered by the terms 'academic achievement' and 'academic attainment'. The three concepts were then mapped out and text searched for on the PsycINFO database (See Table 3). The reason for selecting PsycINFO at this stage was that it has been described as being "one of the highest quality databases from a user perspective" and it allows for terms to be extensively mapped to subject headings which is useful both for identifying other possible concept terms for inclusion as well as assessing what the potential could be for irrelevant hits when selecting a term (Taylor et al., 2015, p.47).

Table 3: Mapping index terms and text terms as operationalized on PsycINFO database

-
1. caregivers/
 2. caregiver*.mp.
 3. care giver*.mp.
 4. carer*.mp.
 5. care*.mp.
 6. 1 or 2 or 3 or 4 or 5
 7. (young adj3 carer*).mp.
 8. (young adj3 care giver*).mp.
 9. (young adj3 caregiver).mp.
 10. (young adj3 care*).mp.
 11. (youth adj3 care*).mp.
 12. (youth adj3 carer*).mp.
 13. (youth adj3 caregiver*).mp.
 14. (child* adj3 carer*).mp.
 15. (child* adj3 caregiver*).mp.
 16. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
 17. 7 or 8 or 9 or 12 or 13 or 14 or 15
 18. education/ or high school education/ or higher education/ or middle school education/ or secondary education/
 19. education*.mp.
 20. exp Colleges/
 21. college*.mp.

22. schools/ or charter schools/ or graduate schools/ or high schools/ or middle schools/ or nongraded schools/ or technical schools/
 23. school*.mp.
 24. universit*.mp.
 25. Training/
 26. exp adult education/
 27. learning/
 28. learning.mp.
 29. exp academic achievement/
 30. (academic* adj3 achiev*).mp. -
 31. educational attainment.mp.
 32. academic failure/
 33. academic failure.mp.
 34. (academic* adj3 underachiev*).mp.
 35. exp Academic Aptitude/
 36. academic aptitude.mp.
 37. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 36
 38. young person.mp.
 39. child*.mp.
 40. adolescen*.mp.
 41. juvenile*.mp.
 42. young adult*.mp.]
 43. young people.mp.
 44. teenager*.mp.
 45. 38 or 39 or 40 or 41 or 42 or 43 or 44
 46. young carer*.mp.
 47. young care giver*.mp.
 48. young caregiver*.mp.
 49. child carer*.mp.
 50. child caregiver*.mp. #
 51. 46 or 47 or 48 or 49 or 50
 52. 51 and 37
 53. 37 and 16
 54. 37 and 17
 55. limit 54 to english language
 57. 37 and 5 and 45
 58. child.mp.
 59. children.mp.
 60. 38 or 40 or 41 or 42 or 43 or 44 or 58 or 59
 61. 37 and 5 and 60

This exercise allowed terms to be scoped for relevance and other terms to be identified; based on this and further consultation with examples of systematic reviews from The Cochrane Library, concept terms were amended to:

1. Caregiver* OR carer* OR care giver*
2. Education* OR college* OR school* OR universit* OR training OR learning OR academic*adj3 (achiev* OR attain* OR failure* OR underachiev* OR aptitude)
3. Child OR youth OR young

The term 'care*' was not included in these refined concept terms based on the example of Lins et al., (2014), Legg et al., (2011), and Vernooij-Dassen et al., (2011); including the term 'care*' on its own whilst including terms such as 'education' and 'young' has the potential to retrieve high levels of irrelevant information, for example on careers, and it was believed

through using the terms 'carer*' and 'caregiver*' results would be more specific (Lins et al., 2014; Legg et al., 2011; Vernooij-Dassen et al., 2011). Similarly, including the search term 'child' as 'child*' can retrieve unwanted results for example on 'childcare' so the decision was made to use the term 'child' without truncation, to focus the search and further reduce irrelevant results. Based on the example of Eccleston et al., (2015) it was also decided that 'youth' would be adopted as an inclusive group term for adolescent*, juvenile and teenager.

Using the NEAR operator

When this three concept term search was applied to ASSIA it led to over three thousand results being returned so as a means to add more precision to the search, the NEAR proximity operator was included (Tompson and Belur, 2015; Taylor et al., 2003). The operator NEAR can be used "to search for terms that are within a given number of terms of each other, but not necessarily as a defined phrase" (Taylor, 2007, p.174). This was tested during the mapping of index terms and text terms in PsycINFO and deemed to be a compromise between searching using two concept groups which produced small numbers of results and searching using three concepts which greatly increased the sensitivity of the search but yielded a high volume of results not relevant to the topic. The rationale for using ASSIA for the exercise below was based on several factors. Following initial scoping exercises (see Table 2), ASSIA returned the highest number of relevant articles of the four databases tested. This database indexes approximately 500 journals. This is more than BEI but less than SSA and ERIC and automatically makes results numbers more manageable without any operators in place to balance sensitivity and precision. ASSIA also uses the ProQuest search platform which is user friendly and as this is the same search platform used in three of the databases included in this study (ASSIA, ERIC and SSA) there would be ease of replication.

To test the use of the NEAR operator the following search formula was constructed and applied to the ASSIA database (date of search 20 November 2015):

(young NEAR/3 carer* OR young NEAR/3 care giver* OR young NEAR/3 caregiver* OR child NEAR/3 carer* OR child NEAR/3 caregiver* OR youth NEAR/3* carer* OR youth NEAR/3 caregiver*) AND (education* OR college* OR school* OR universit* OR training OR learning OR "academic NEAR/3 (achiev* OR attain* OR failure OR underachiev* OR aptitude)") AND la.exact ("ENG")

It should be noted that the term 'care giver' is only present in this formula alongside the term 'young' because it was identified as a particular phrase referring to young carers as 'young care givers'. To apply this alongside the terms 'child' and 'young' increases the return of irrelevant results focusing on the topic of childcare.

When this formula was applied to ASSIA, one thousand four hundred and sixty one articles were retrieved, thirty of which were deemed relevant. To test scientifically the effectiveness of using this style of search, relevant results were cross-referenced with the relevant articles retrieved during the initial scoping exercise in the ASSIA database (Table 2). Cross-referencing highlighted that only twenty five of the thirty relevant articles were retrieved

from the original search using two concepts with four unique relevant results also present. To ascertain why five relevant articles were missing in this search, abstracts for these articles were consulted and it was found that in each of the articles 'young carer' and 'education' or 'school' or 'university' was highlighted as an identifying term raising concerns over the formula structure where all of these terms were already present.

Upon closer examination, to give the search more precision, brackets were added around each young /child /youth and carer*/caregiver*/caregiver*combination making each into individual entities grouped within brackets to join the terms together as one concept. The search terms regarding academic achievement /underachievement /attainment were made into individual search terms in brackets within the education concept aspect of the formula. The amended formula was applied as follows (date of search 27 November 2015):

((young NEAR/3 carer*) OR (young NEAR/3 care giver*) OR (young NEAR/3 caregiver*) OR (child NEAR/3 carer*) OR (child NEAR/3 caregiver*) OR (youth NEAR/3 carer*) OR (youth NEAR 3/caregiver*)) AND (education* OR college* OR school* OR universit* OR training OR learning OR (academic NEAR/3 achiev*) OR (academic NEAR/3 attain*) OR "academic failure" OR (academic NEAR/3 underachiev*) OR "academic aptitude") AND la.exact ("English")

The same cross-referencing exercise was then repeated and all thirty relevant articles were retrieved from the original search using two concepts plus the same four unique relevant results from the search utilising the NEAR operator.

It must be concluded that due to the inclusion of the terms 'carer' and 'caregiver' in concept search terms, it is somewhat unavoidable that results will be returned using the definition of 'carer' or 'caregiver' as being in reference to next of kin, parent/guardian, or teacher alongside articles focusing for example on children in care or children with disabilities. This ambiguity was displayed in the following way during this search:

- 'parent/carers', 'parents/caregivers', 'caregiver-child', 'caregivers of children'
- 'children in care', 'looked after children', 'in primary care', 'foster care', 'foster carers', 'foster children'

An additional way of reducing the number of irrelevant results and consequently limiting the ambiguity of terms is to exclude certain studies from the search (Taylor et al., 2003). In the case of this topic, the studies that were sought to be eliminated from the search results were those relating to 'foster care*', 'looked after children' and 'children in care'. These studies were excluded from results using the NOT operator. Each study was removed from search results as an individual set so as to not complicate the search formula (See Appendix C). As the use of NOT in this manner has been described as needing a "note of caution", as each study was removed it was checked that all relevant articles were still present and after the removal of all three studies it was found that all relevant studies were still present (Taylor et al., 2015).

Returning to a two concept search strategy

Testing using three concept groups in ASSIA, with the NEAR operator employed to improve the precision of the search, did increase by four the number of relevant hits being returned compared to the original two concept search on the same database. Retrieving irrelevant results through applying a three concept group search with the NEAR operator was to be expected, however the extent to which this occurred resulted in search precision becoming greatly reduced at 2.2%.

Table 4: Comparing two concept and three concept NEAR searches on ASSIA

Database & Date of Search	Number of Concepts Used	Formula	Total Hits Retrieved	Number of Relevant Hits	Precision (%)
ASSIA 09/11/2015	2 concepts	("young carer*" OR "young caregiver*" OR "child carer*") AND (education OR school OR university OR employment OR training OR learning)	42	30	71.4
ASSIA 27/11/2015	3 concepts using 'NEAR' Operator	((young NEAR/3 carer*) OR (young NEAR/3 caregiver*) OR (young NEAR/3 caregiver*) OR (child NEAR/3 carer*) OR (child NEAR/3 caregiver*) OR (youth NEAR/3 carer*) OR (youth NEAR/3 caregiver*)) AND (education* OR college* OR school* OR universit* OR training OR learning OR (academic NEAR/3 achiev*) OR (academic NEAR/3 attain*) OR "academic failure" OR (academic NEAR/3 underachiev*) OR "academic aptitude") AND la.exact ("English"))	1561	34	2.2

This comparison exercise outlined in Table 4 illustrates the contrast between the precision of the two concept search strategy and the three concept search strategy using the NEAR operator. To summarise, there was a 69.2% reduction in precision for an additional 11.8%

(four) relevant hits when moving from a two concept search strategy to a three concept strategy. As the focus of this study is on balancing sensitivity and precision, seeking to minimise irrelevant results and retrieving all relevant results, and that this is a time bound study⁵, continuing with a three concept search strategy using the NEAR operator was not a viable option. Such a small return on relevant articles could be identified through the citations of articles classified as relevant and a search of grey material without search precision being so significantly impacted.

Following the decision to return to searching using two concepts, the following search structure was used after finalising during the scoping exercise outlined in Table 2.

1. "young carer*" OR "young care giv*" OR "young caregiver*" OR "child carer*" OR "young adult carer"
2. Education OR education* OR school OR school* OR university OR universit* OR employment OR training OR learning

Truncation was added to the terms 'education', 'school' and 'university' to increase sensitivity. After further reading of Cochrane reviews on carers, the terms 'young care giver*' and 'young caregiver*' were amended to "young care giv*" and "young caregiver*" (Candy et al., 2011). Following the review of articles returned previously, the decision was also made to re-admit the term 'employment' into the search structure as a link was noted between the future aspirations, employment and qualifications of young carers (Aylward, 2009; Warren, 2005).

Before these concept terms were applied to the remaining databases and the web search engine Google Scholar, for consistency and thoroughness, the formulas already finalised for ASSIA, SSA, BEI and ERIC were tested with the addition of the new truncation operators. This exercise did not yield any relevant additional articles on any of the four databases so their final formulas remain unchanged to those described in Table 2.

Table 5 outlines the final search formulas which were formulated by applying and testing the above concept terms on each individual database, which explains the variance in formulas across the different databases. As before, the NOT operator was used to assess the impact of including a term in the final search formula (Taylor et al., 2015; Best et al., 2014).

Table 5: Details of the final search formulas

ASSIA	09/11/2015	("young carer*" OR "young caregiver*" OR "child carer*") AND (education OR school OR university OR employment OR training OR learning)
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⁵The amount of time needed to review and assess abstracts for relevance to the inclusion criteria was three and a half days for one thousand five hundred and twenty five articles.

BEI	11/11/2015	("young carer*" OR "young adult carer*") AND (education OR school OR university)
ERIC	12/11/2015	("young carer*" OR "child carer*" OR "young caregiver*") AND education
PsycINFO	13/01/2016	("young carer*" OR "young caregiv*" OR "child carer*" OR "young adult carer*") AND (education* OR school* OR learning)
SSA	06/11/2015	("young carer*") AND (education OR school OR university OR "caregiver burden")
Scopus	18/01/2016	("young carer*" OR "young care giv*" OR "young caregiver*" OR "child carer*" OR "young adult carer*") AND (education* OR school* OR employment OR training)
Social Care Online	11/01/2016	("young carer") AND (education OR school OR university OR employment)

Applying a two concept search to Google Scholar

Rather than relying on the Boolean Operators AND and OR utilised in previous database searches, advanced searching on the web search engine Google Scholar is structured as illustrated in Figure 1.

The screenshot shows the Google Scholar Advanced Search interface. On the left, there are radio button options for search criteria: 'Find articles with all of the words', 'with this exact phrase', 'with at least one of the words', 'without the words', and 'where my words occur'. The 'with this exact phrase' option is selected. Below these are fields for 'Return articles authored by', 'Return articles published in', and 'Return articles dated between'. The main search input field on the right contains the following text: "young carer" OR "young care giver" OR "young caregiver" OR "child carer" OR "young adult carer" AND (education school university employment training le). Below the search field is a 'Copy to clipboard' button. At the bottom left is a blue search button with a magnifying glass icon.

Figure 1: Google Scholar Advanced Search Options displaying final search strategy

Initially, individual young carer concept terms were tested in the 'with the exact phrase' field using quote marks to focus the search and the first four hundred hits checked for relevance to the topic under study. Due to lack of precision displayed in this scoping exercise of the 'exact phrase' "child carer" (seventeen out of four hundred or 0.04% of results were relevant to the topic of a young person providing care for a sick or disabled relative), it was decided not to include this term in the final search strategy. Each young carer term was then tested in the 'with the exact phrase' field alongside the 'with at least

one of the words' section containing all education concept terms and the relevance of results to the topic was assessed.

The final search strategy adopted for Google Scholar was to use the Advanced Search Options and insert in 'with the exact phrase' the terms "young carer" OR "young care giver" OR "young adult carer" OR "young caregiver" alongside the terms 'education school university employment training learning' in the search section titled 'with at least one of the words'. The Boolean operator OR can only be applied in the 'with the exact phrase' field of this search (as shown in Figure 1 above). It should be noted that due to this being a time-bound study, the sequence order that concepts were added into Google Scholar were not applied in any other order to the way they are outlined above; doing so may return different results due to Google Scholar being a web search engine and this should be noted by other researchers / librarians undertaking systematic searches in Google Scholar.

Results included 'citations', which Google Scholar authors describe as "articles which other scholarly articles have referred to, but which we haven't found online" (Google Scholar, No date). Such references can be excluded from search results via Google Scholar settings. However, as no filters were placed on other databases aside from sort by relevance and in the English language only, this was not applied to the Google Scholar search. Citations where there was no link or further details, even if the title looked promising, were not included as a relevant hit, but details were noted for follow up hand searches.

Relevant hits were sought in the first one hundred, two hundred, and three hundred search results following the example of McFadden et al., (2012) with precision and sensitivity calculated at each stage as a means to assess the rationale for continuing to analyse search results for relevant and unique hits (McFadden et al., 2012). This led to the decision to continue analysing up to the level of four hundred search results, following search results between two hundred and three hundred showing a growth in sensitivity. By search result four hundred sensitivity levels had stabilised and only one unique hit was identified. The results of these calculations appear in the results tables as GS100, GS200, GS300, GS400, when calculating overall sensitivity of results only GS400 figures are included.

Results

Number of relevant items and unique hits retrieved

After cross-referencing to ensure articles had been consistently classified adhering to the inclusion criteria throughout all seven database search results and those of Google Scholar, and once duplicate articles or "overlap between databases" (McFadden et al., 2012, p.630) were removed, one hundred and eighty one relevant articles had been retrieved overall. This number was then used to calculate the sensitivity of each database search and the results of these calculations alongside the number of unique hits present, and the precision of each database, is outlined in Table 6.

Table 6: Results of database searches

Database	Date of Search	Total Retrieved	Hits	Number of Relevant Hits	Unique Relevant Hits	Sensitivity %	Precision %
ASSIA	09 Nov 2015	42*		30*	8	16.6	71.4
BEI	11 Nov 2015	10*		9*	5	5.0	90.0
ERIC	12 Nov 2015	36*		19*	6	10.5	47.2
GS100	30 Jan 2016	100*		41*	24	22.7	41.0
GS200	30 Jan 2016	200*		57*	30	31.5	28.5
GS300	30 Jan 2016	300*		71*	35	39.2	23.7
GS400***	30 Jan 2016	400*		73*	36	40.3	18.3
PsycINFO	13 Jan 2016	41*		22*	5	12.2	53.7
SCO	11 Jan 2015	148*		81*	64	44.8	54.7
Scopus	18 Jan 2015	107*		38*	12	21.0	35.5
SSA	06 Nov 2015	32*		15*	0	8.3	46.9
Total		816*		181**			

Note: * is used to identify that number includes duplicates between databases; total number of relevant hits with duplicates removed can be identified by ** (Best et al., 2014, p.352). ***Only GS400 was used to calculate total hits retrieved, sensitivity and for comparison with results from other databases (McFadden et al., 2012, p.631)

Table 7: Ranking of databases based on unique hits

Database	Unique Hits Ranking	Unique Relevant Hits
SCO	1	64
GS400	2	36
Scopus	3	12
ASSIA	4	8
ERIC	5	6
BEI	6	5
PsycINFO	6	5
SSA	7	0

Table 7 shows that Social Care Online produced the highest number of unique relevant hits with 64. This was 28 unique hits more than Google Scholar with 36, followed by Scopus with 12, ASSIA with eight, ERIC with six and BEI and PsycINFO both with five. SSA had no unique relevant hits identified. Of the fifteen relevant hits contained in SSA, nine were returned by ASSIA and GS400, six by PsycINFO and Scopus, four by SCO, three by ERIC and one by BEI.

Sensitivity and precision

Social Care Online had the highest level of sensitivity at 44.8%, closely followed by GS400 with 40.3%. Much lower, in third place with 21.0% was Scopus, then ASSIA with 16.6%, PsycINFO with 12.2%, ERIC with 10.5% and SSA with 8.3%. BEI had the lowest level of sensitivity with 5.0%. The average level of sensitivity overall was 19.8% (See Table 8 below).

Table 8: Ranking of databases based on sensitivity

Database	Sensitivity Ranking	Sensitivity %
SCO	1	44.8
GS400	2	40.3
Scopus	3	21.0
ASSIA	4	16.6
PsycINFO	5	12.2
ERIC	6	10.5
SSA	7	8.3
BEI	8	5.0

BEI had the highest level of precision at 90.0%, followed by ASSIA at 71.4%. Social Care Online and PsycINFO performed similarly with 54.7% and 53.7% respectively. Likewise the precision levels of ERIC (47.2%) and SSA (46.9%) had only a 0.3% difference. Scopus was next at 35.5% and GS400 had the lowest level of precision with 18.3%. The mean level of precision overall was 52.2% (See Table 9).

Table 9: Ranking of databases based on precision

Database	Precision Ranking	Precision %
BEI	1	90.0
ASSIA	2	71.4
SCO	3	54.7
PsycINFO	4	53.7
ERIC	5	47.2
SSA	6	46.9
Scopus	7	35.5
GS400	8	18.3

Types of relevant articles

Of the one hundred and eighty one relevant articles identified, one hundred and fifteen were empirical studies (63.5%), twenty-eight were literature reviews (15.5%), twenty-three were policy documents (12.7%), and fifteen (8.3%) were classified as 'other'. The classification of 'other' was assigned to articles that outlined training or guidance on how to help young carers in education where, on closer examination, they could neither be deemed policy or a literature review.

Table 10: Types of relevant articles in individual databases

Database	Total Retrieved	Hits	Relevant Hits	Number of Policy Documents	Number of Literature Reviews	Number of Empirical Studies	Number of 'Other' documents
ASSIA	42*	30*	0	7*	23*	0	
BEI	10*	9*	0	2*	6*	1*	
ERIC	36*	19*	2*	3*	13*	1*	
GS400	400*	73	2*	14*	51*	6*	

PsycINFO	41*	22*	0	3*	19*	0
SCO	148*	81*	17*	10*	44*	10*
Scopus	107*	38*	0	6*	31*	1*
SSA	32*	15*	0	3*	12*	0
Total	816*	287*	21*	46*	201*	19*

Note: * is used to identify that number includes duplicates between databases

Discussion

The databases and web search engine Google Scholar selected as search tools for this study can be categorised as falling into five categories: education (ERIC, BEI), social work/social policy (ASSIA, SSA, SCO), psychology (PsycINFO) and multidisciplinary (Scopus, Google Scholar). Despite the inclusion criteria being on young carers and education, it was the databases that were social work/social policy and multidisciplinary in nature that returned the largest quantity of relevant hits, not those databases selected from the field of education. It could be argued that this highlights the multidisciplinary nature of the subject in question; potentially the lack of research explicitly on young carers and education; or the limited coverage of ERIC and BEI in relation to certain education topics. BEI had high precision demonstrating a good thesaurus of search terms, but the low sensitivity suggests limited coverage of relevant journals.

One limitation of the study is that while systematic reviews in the Cochrane Library were consulted during the process of identifying and selecting search terms, reviews of the EPPI-Centre and the Campbell Collaboration were not utilised for this purpose. This is something that academic librarians may wish to consider for undertaking systematic reviews in the future.

Social Care Online with 64 and Google Scholar with 36 returned the highest number of unique hits. In relation to sensitivity, Social Care Online and Google Scholar were ranked first and second respectively. However, when it came to precision, Google Scholar was ranked last and Social Care Online was ranked third (this being due to the high number of total hits retrieved by Google Scholar). Social Care Online returned 45% of the one hundred and eighty one documents identified overall, closely followed by Google Scholar with 40%. Google Scholar identified more documents than Social Care Online that were returned by other databases (37) and had a similar number of unique hits (36). Social Care Online identified 17 documents present in other database results but had a much higher level of unique hits than Google Scholar. Further analysis of search results from Social Care Online and Google Scholar showed that had they been the only two databases used in this study, between them they would have returned 141 (78%) of the 182 documents identified across the seven databases.

The precision scores were high compared to similar studies cited above, attributed to the attention to detail in search construction. Each database had all concept terms tested on them, with any additional results retrieved through the addition of a term identified for examination using the NOT operator. If a term yielded a relevant result it was included in

the final search formula even if irrelevant ones were returned as well. Although in a systematic review for the Cochrane or Campbell Collaborations sensitivity is paramount at the expense of precision, for other review purposes – such as grant applications and PhD theses – this is not realistic given the number of irrelevant hits that will be retrieved. This article provides an exemplar for considering the dimension of precision as well as sensitivity in searching systematically for ‘everyday’ review purposes.

The value of the ‘unique relevant hits’ metric is that it enables a consideration of how many hits would be lost if certain databases were not used. In this case there was a large margin between the four databases with the fewest unique relevant hits. If these (ASSIA, BEI, ERIC, PsycInfo) were not used, 24 of the 181 relevant articles would not have been retrieved. Thus, the other three databases (SCO, Scopus, SSA) plus Google Scholar between them would have retrieved 87% of the hits retrieved by this search across seven databases plus Google Scholar. An accumulation of this type of knowledge will be invaluable to researchers and librarians wanting to select the most appropriate databases for searching where time and resources are not unlimited (Best et al., 2014; McFadden et al., 2012).

Social Care Online showed itself in this study to be a valuable source of information, ranking first in sensitivity and number of unique hits, however if the search platform and saving options were more like those of Scopus and PsycINFO it would more user friendly. Currently it has no recent search option, unless searches are saved, and sets of formulas cannot be easily combined.

The web search engine Google Scholar had the second highest number of unique hits overall and was ranked second for sensitivity. When analysing results in Google Scholar, the work of McFadden et al., (2012) was used as a comparator in relation to how many search results should be examined, (up to three hundred search results were included in McFadden et al., (2012). The present study required up to four hundred search results to be examined due to sensitivity increasing substantially between GS200 and GS300 (see Table 6). Further research is required to determine the optimal number of hits to appraise when using web search engines which return large numbers of hits of diminishing utility. The method used here is to calculate sensitivity and precision for one hundred search results at a time and identify the unique hits up to the point where sensitivity stabilises and perhaps up to the point where unique hits are no longer identified (McFadden et al., 2012). At present, intervals of 100 hits seems appropriate; in future this might be fine-tuned to smaller intervals for appraisal of web search engines.

For inclusion in a systematic review, it is more efficient if results can be saved and abstracts are available for all articles. This is problematic for Google Scholar, and there is no guarantee that results will be accessible again at a later date (Boeker et al., 2013). An important element to systematic reviews is that the searches can be replicated by others. The absence of abstracts makes classifying results time consuming as full articles very often had to be accessed to make a decision. Accessing full texts via Google Scholar was problematic when an article had a bad link and could not be retrieved (Bergman, 2012). The

'All Versions' option was helpful in these situations, providing a different successful link to the article; however, it was also found that when attempting to access articles via 'Springerlink' one was unable to return to the original search results. Instead it was necessary to re-enter the search, which could raise questions over the validity of sensitivity calculations for each 100 results analysed since search results vary in each search carried out. Several documents were also found during the classification process to have the same content but different titles.

When the option was given to choose between using ProQuest and EBSCO Host as the platform through which to search ERIC, ProQuest was chosen due to its layout, user-friendly saved search options, and easier navigation. Problems were however experienced with ProQuest in relation to ASSIA and duplicate articles. When a saved search was run, the figure given for the number of results returned included duplicates even when the original search that was saved excluded them. As abstracts were consulted it was observed that no more abstracts would be displayed, yet the figure of abstracts viewed and overall figure given for search results were different, with the number of abstracts viewed being less than the figure given overall for search results. After manually re-entering the same search and investigating through the 'help' section it was confirmed that the difference in numbers was due to the inclusion and subsequent removal of duplicate articles.

Throughout database searches, particularly in Scopus, ASSIA, SSA, BEI and ERIC, the concept terms 'university', 'school' and 'education' were highlighted in abstract/search details even when they were only contained in the authors details and there was no apparent link between the article to the topic of young carers and education. Due to the review topic it is unavoidable to exclude terms from concept groups, but it raises questions about how some topics are indexed on these particular databases.

The Boolean operator NOT was invaluable throughout the formulation of search formulas as a means to test the addition of terms to the final formula and was tested on all databases (Taylor et al., 2015).

Conclusion

Full-scale systematic reviews such as for the Cochrane and Campbell Collaboration libraries require a paramount focus on sensitivity to the disregard of precision. However, for almost all other purposes, cognisance needs to be paid to some optimisation between sensitivity and precision. Due to the limitations of time and resources, reviews for grant applications and PhD theses need to be based on reasonable scope. The methods and metrics illustrated here provide tools for undertaking this task in a rational manner. This paper has demonstrated some of the methods that may be developed to support academic librarians and researchers in developing robust searches, and in making informed decisions about optimal choices about database selection. This paper will assist academic librarians think through the issues involved in creating effective and efficient concept groups in their research support roles, and in determining the number and range of databases to search.

The 'unique relevant hits' metric is useful to elucidate additional dimensions of these choices. The paper has also illustrated some of the challenges involved and the knowledge and skills required to progress robust approaches to systematic literature searching. With the 'information explosion' the task and the challenges involved in retrieving relevant research efficiently will become more demanding. The skills illustrated in this paper will become ever more crucial for reviews to have credibility.

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Appendix Two - Survey



Young Carers and Education in Northern Ireland

Dear (Insert Name),

My name is Allison Campbell and I am researching 'The educational impact of being a young carer aged 16-24 years old in Northern Ireland'.

I would like to learn more about your experiences of providing care, assistance or support to a family member with a health condition in Northern Ireland, I am particularly interested on the impact this caring role has had upon your education.

I would be grateful if you would complete the enclosed questionnaire and return it in the pre-paid envelope by _____.

The questionnaire should take you approximately 20 minutes to complete and your answers will be treated confidentiality and anonymously. In completing this questionnaire, you should be aware that:

- Your participation is entirely voluntary
- You are free to refuse to answer any question
- You are free to withdraw from completing the questionnaire at any time
- The contents of the questionnaire will be kept strictly confidential
- Sections from the questionnaire may be made part of the final report; but you will not be identified

- The questionnaires will be held securely and will be destroyed on completion of the study

In ticking this box, you agree to be a participant in this research []

Please make sure that the consent form attached behind this page is completed.

I hope that you will consider participating in this research, and I would like to thank you in advance for your valuable contribution. If you wish to discuss any aspect of the study please do not hesitate to contact me via email at Campbell-A62@ulster.ac.uk.

Yours Sincerely,

Allison Campbell

Section One: About your caring role

1. Who are you providing a caring role for within your family home? (Please tick as many as applicable)

Mother	
Father	
Brother	
Sister	
Grandmother	
Grandfather	
Other	

- 1a. If you selected 'Other' in the options above please give details below

2. What type of health condition do they have? (Please tick as many as applicable and give brief details in the space following)

Physical illness (For example Cancer, Diabetes, Epilepsy, Heart Disease,) (Please give details below)	
Physical disability (For example Multiple Sclerosis, Spinal Injury) (Please give details below)	
Poor mental health	
Learning disability	
Hearing or visually impaired	
Addictive illness (alcohol, substance)	

Other (Please give brief details below)	
---	--

3. When do you provide your caring role for this/these family member(s) within your family home? (Please tick as many as applicable)

Before School/College	
After School/College	
Before Work	
After Work	
At Weekends	
During Holiday Times	

4. How many days a week do you provide a caring role for this/these family member(s) you live with? (Please tick the most appropriate option)

7 days a week	
6 days a week	
5 days a week	
4 days a week	
3 days a week	
2 days a week	
1 day a week	
Only occasionally when required	

5. Approximately how many hours do you estimate you provide care for this/these family member(s) you live with each week? (Please estimate and tick the most appropriate option)

1-5 hours a week	
6-10 hours a week	
11-15 hours a week	
16-20 hours a week	
21-25 hours a week	
26-30 hours a week	
31-35 hours a week	
36-40 hours a week	
Over 40 hours a week	
Unsure	

5a. If you selected 'Over 40 hours a week', please specify the approximate number of hours you estimate you are providing care

6. How long have you been providing a caring role for this/these family members you live with? (Please tick the most appropriate option)

1 year or less	
2 -3 years	
4-5 years	
6-7 years	
8-9 years	
10-11 years	
12-13 years	
14-15 years	
16-17 years	
18-19 years	

7. What types of tasks do you carry out in your caring role at home and how often?
(Please indicate your response beside each task-stating if it is always, sometimes or never).

	Task	Never	Sometimes	Always
a.	Cleaning			
b.	Cooking			
c.	Washing dishes/loading or unloading dishwasher			
d.	Washing Clothes/ Ironing			
e.	Doing the family food shop			
f.	Work part time to contribute to the family income			
g.	Help person you care for bank money, pay bills or collect benefits			
h.	Taking the person you care for to medical appointments			
i.	Help interpret for or communicate for the person you care for			
j.	Help the person you care for dress/undress			
k.	Help the person you care for wash and/or use the bathroom			
l.	Help the person you care for with their medication and/or dressings			
m.	Keep the person you look after company			
n.	Checking on the person you care for			

o.	Going out with the person you care for to make things easier for them/help make sure they are safe			
p.	Help look after brothers and sisters on your own			
q.	Help look after your brothers and sisters while a parent or other adult is nearby			

Section Two: About your education

1. Are you currently...? (Please tick the statement most relevant to you and give further details below as applicable).

At School	
At a Regional College	
On an Apprenticeship course (Please give details below)	
On a training scheme(Please give details below)	
In full time employment and not in education (Please give details below)	
In part time employment and not in education (Please give details below)	
At University (Please give details below)	
Not in Education, Employment or Training	

2. If you are still at school or at a Regional College, which statement best describes the stage you are at? (Please tick the statement most relevant to you).

Waiting to sit GCSE Examinations	
Working towards As/A-Levels	
At another stage (please give details below)	

3. What is the highest level of qualification you have achieved? (Please select from the following and give further details below if applicable)

GCSE	
As Level	
A Level	
BTEC	

Certificate	
Diploma (NVQ's/VRQ's)	
HNC/HND/Foundation Degree	
Bachelor's Degree	
Other (Please give details below)	

4. If you have completed GCSE's please list all the subjects you completed and the grade you have received.

GCSE Subject	Grade Awarded

5. If you have completed As Levels please list all the subjects you completed and the grade you have received.

As Level Subject	Grade Awarded

6. If you have completed A Levels please list all the subjects you completed and the grade you have received.

A Level Subject	Grade Awarded

7. Do you feel that your caring role impacted on the grades you received?

Yes	
No	
Somewhat	
Unsure	

8. If you answered 'yes' or 'somewhat' to the previous question, could you please give brief details/the reasons behind your choice.

9. Do you feel that the decisions or choices you have made about your future education have been impacted on by your caring role?

Yes	
No	
Somewhat	
Unsure	

10. If you answered 'yes' or 'somewhat' to the previous question, could you please give brief details behind your choice.

11. To be completed only if you receive Education Maintenance Allowance

Have your Education Maintenance Allowance Payments ever been impacted on by you having to take time off from your place of education because of your caring role?

Yes	
No	

12. If you answered 'yes' to the previous question, could you please give details about your experience below?

Section Three: Support Received

1. Did you receive help/support in relation to your education from any of the following people/organisations because they knew you were caring for someone? (Please tick all those applicable and rank in order of biggest support with '1' being your biggest source of support.)

	Tick if received support from	Please rank source of support (1=biggest source of support)
Other family members		
Friends		
Neighbours		
Class Teacher		
Pastoral Care Teacher		
School Nurse		
Educational Welfare Officer		
Social Worker		
Homework Club		
Young Carers Organisation		
Other		

- 1a. If you answered 'Other' to the previous question, could you please give details about from who else/where else you received help/support in relation to your education because they knew you were caring for someone?

- 1b. If you answered that a Young Carers Organisation helped you with your education, could you please give details about how they did this?

-
2. If you are aged sixteen and over and are not in full-time education, do you receive carers allowance? (Please tick the appropriate response).

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

To be completed if you answered 'yes' to question 2

- 2a. If you do receive carers allowance, for approximately how long have you received this allowance?

Section Four: Not in Education Employment or Training

To be completed if you are not in Education, Employment or Training

Please select the response most applicable to you in regards to the following statements

1. I am not in Education, Employment or Training...

By choice	
Not by choice	

2. I am not in Education, Employment or Training ... ((Please tick all those applicable and rank in order of what is most relevant to your situation with '1' being most relevant)

Because of lack of qualifications	
Because of Caring Responsibilities	
Because I am a full time carer by choice	
Because I am a full time carer not by choice	
This is not because of my caring role	

Section Five: Education and Your Caring Role

To be completed by all survey participants

This section is to be completed by every participant and, depending on your age, relates to both your current or past school/education experiences. The phrase 'place of education' refers to school, further education and higher education.

Please circle the response to each statement that is most relevant to you

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
My place of education is/was somewhere I feel/felt free from my caring role	1	2	3	4	5

My place of education is/was a break from my caring role	1	2	3	4	5
My place of education is/was somewhere that adds/ added to my problems	1	2	3	4	5
My educators know/knew about my caring role	1	2	3	4	5
I feel/felt that those educating me understand/understood my caring role	1	2	3	4	5
I feel/felt supported in my caring role by my educators	1	2	3	4	5
I feel I receive/have received the support I need/needed from my educators	1	2	3	4	5
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I want/I wanted my place of education to know about my caring role	1	2	3	4	5
When my place of education was made aware of my caring role they treated this information confidentially (If applicable)	1	2	3	4	5
I feel like I am/I was treated like an adult at home	1	2	3	4	5
I feel like I am/I was treated like a child in my place of education	1	2	3	4	5
I have/had a positive attitude towards my education	1	2	3	4	5

My caring role has not impacted on my education	1	2	3	4	5
I feel my career prospects have been impacted on by my caring role	1	2	3	4	5
My caring role has had little impact on my education	1	2	3	4	5
My caring role has had a significant impact on my education	1	2	3	4	5
My caring role takes priority/took priority over my schoolwork/education	1	2	3	4	5
My caring role has impacted on the choices I have made regarding further and higher education	1	2	3	4	5
My caring role has impacted on my choice of career (if not in education)	1	2	3	4	5
Because of my caring role I have had to take time off from my place of education	1	2	3	4	5
I have been late to my place of education because of my caring role	1	2	3	4	5
I have/had problems concentrating at school etc. because I am/was thinking about the person I provide care for at home	1	2	3	4	5
I feel/felt tired at school etc. because of my caring responsibilities at home	1	2	3	4	5

I have considered dropping out of my education because of my caring responsibilities	1	2	3	4	5
I have experienced problems completing homework/coursework because of my caring role	1	2	3	4	5
I feel my grades/marks were impacted on by my caring role	1	2	3	4	5
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I cannot/ could not afford the required text books for my course	1	2	3	4	5
I cannot/could not afford to buy lunch at my place of education	1	2	3	4	5
My caring role stops/stopped me participating in extra-curricular activities	1	2	3	4	5
My caring role impacts/impacted more on me spending time on extra-curricular activities than on my homework	1	2	3	4	5
My caring role impacts/impacted more on me spending time with friends than on my homework	1	2	3	4	5
I cannot/could not afford to take part in extra-curricular activities	1	2	3	4	5
I have experienced bullying at my place of education because of my caring role	1	2	3	4	5
I have experienced bullying at my place of education because of the	1	2	3	4	5

stigma attached to the illness of the person I provide care to					
Some people in my place of education have a negative attitude towards the illness of the person I provide care to	1	2	3	4	5
I feel my caring role contributes/contributed to me feeling lonely at my place of education	1	2	3	4	5
I feel my caring role contributes/contributed to me feeling isolated at my place of education	1	2	3	4	5

Following the statements you have just responded to, if you have any further comments to add please use the space below. (Should you need more space please feel free to write on the back of this page).

Section Six: About you

1. What age are you?

2. Are you Male or Female?

3. How many family members live in your family home? (Please provide numbers if applicable for example 2 brothers, 2 grandmothers etc.)

Family Member	Numbers of (if applicable)
Mother	
Father	
Sister	
Brother	
Grandmother	
Grandfather	
Aunt	
Uncle	
Cousin	
Other	

If selected 'Other', please specify_____

4. How many brothers and sisters do you have and what age are they? (Please insert a number in the relevant box below)

	Age of Brother
Brother 1	

Brother 2	
Brother 3	
Brother 4	

Brother 5	
	Age of Sister
Sister 1	
Sister 2	
Sister 3	
Sister 4	
Sister 5	

5. What is your postcode?

Thank you for giving of your time to complete this questionnaire, it is very much appreciated.

The following section will be removed from the completed questionnaire by your young carers organisation and returned to the researcher in a separate envelope so that your answers will remain anonymous.

Prize Draw

Please complete the following details so that you can be entered into a prize draw to win a High Street Voucher.

Name: _____

Young Carers Organisation: _____

Would you be willing to be interviewed?

If you would be willing to be interviewed about being a young carer and your experiences of education please complete the details section below. If you are under 18 please provide the contact details of your parents/guardians as well.

Name of young person completing questionnaire (to be completed only if you wish to participate in an interview)

Please complete if you are under 18 years old

Name of Parent(s)/Guardian(s)

Contact Telephone Number(s) for Parent(s)/Guardian(s)

Please complete if you are over 18 years old

Please provide a telephone number for you to be contacted on

Contact Telephone Number

Appendix Three – Interview Protocols

Interview Protocol for Young Carers

Background

- What age are you?
- Who lives in the family home with you?

How many brothers and sisters do you have?

What is your position in the family- e.g. oldest/youngest child?

- Who do you provide care for within the family home?
- What is the illness of person being cared for?
- How long have you been providing care to (insert person)?
- When do you provide this caring role? (For example- before school, after school, at weekends?)

Approximately how many days a week/ How many hours?

Education background

- Are you currently in education, employment or training?

If in education- what stage are you at? What qualifications have you completed/are you in the process of completing? What grades did you obtain at GCSE/A Level (if applicable)?

If in employment- what is your current job? What qualifications have you completed? What grades did you obtain at GSCE/A Level (if applicable)?

If in training- what sort of training are you engaged in? What qualifications have you completed? What grades did you obtain at GSCE/A Level (if applicable)?

If not in education, employment or training- What age did you leave school? What qualifications do you have?

Overall experience of education

- Generally, how would you describe your experience of school/education?
- How would you describe your attitude towards education?

- How would you describe the relationship between your caring role and your education?
- Do you think that having a caring role impacted on your education?

If so, in what ways?

If in employment- do you feel that your caring role impacted on the choices you made regarding your career/employment options?

Has your caring role impacted on your career prospects/opportunities?

- If have left school and are attending a regional college, training course or university course-Has your caring role impacted on the choices you have made regarding continuing your education after leaving school?
- Did your place of education know about your caring role?

If the answer was 'No', was there a particular reason for this?

If the answer was 'Yes' -

Did your place of education recognise your caring role?

Were your teachers understanding about your caring role and how this impacts on your daily life?

- If answered 'Yes' or 'No'- How to feel you were treated by your place/places of education?

Caring and their education

- How would you respond to the following statements? (Ask to give details to their responses)

Because of my caring role I have missed school/classes

Because of my caring role I have been late to school/class

I have thought about dropping out of education because of my caring role

I have experienced Bullying at my place of education because of my caring role

I feel that I have been stigmatised in my place of education because of my caring role

I feel that I am stigmatised at my place of education because of the condition the person I care for

My caring role took/takes priority over my schoolwork/education

I have experienced problems concentrating at my place of education because of my caring role

I have experienced problems with tiredness at my place of education because of my caring role

I have had problems completing my homework because of my caring role

I have been unable to attend afterschools/extra-curricular activities because of my caring role

My caring role has impacted on the decisions I have made about my future education/career

Support received

Did you feel supported at your place of education?

What help did you receive to support you with your education? What form did this help take?

Where did this help come from?

Do you feel that you received the help you needed with your education?

If not, what would have helped you more?

Recommendations

- Which type of support really helped you?
- Based on your experience what recommendations would you make about how young carers can best be supported with their education?

Interview Protocol for Professionals Information of Interviewee

Background Information of Interviewee

- What is your job title?
- Could you give me a brief job description please? Numbers of YCs working with?
- How long have you been in your current position?
- Do you have or are you working towards any professional qualifications?

Details of experience working with Young Carers Aged 16-24 Years Old in Northern Ireland

- What experience do you have of working with young carers aged 16-24 years old in Northern Ireland?
- How often do you come into contact with young carer aged 16-24 years old in Northern Ireland? Approximately how many?
- What is the context of this contact?

Experiences of Young Carers and Education

- From your experience could you please outline any instances of young carers in Northern Ireland aged 16-24 years old having problems with their education?

Are there particular areas/issues causing problems for young carers and their education?

- From your experience could you please outline any instances of young carers having a positive experience with their education.
- What has been your experience of building relationships with schools in terms of accessing and working with them re YCs?

Recommendations

Recommendations

- Based on your experience of young carers and their education, have you identified any recommendations that could be implemented to help support their education?
- Is there anyone you would know of with experience of working with YCs this age who you feel it would be helpful/beneficial for me to talk to? e.g. any teachers/youth workers?
- Is there anything else you feel we should have discussed about YCs aged 16-24 years old and their education that we haven't covered?

Appendix Four – Information sheet and consent form for Professionals



Young Carers School of Education and Education in Northern Ireland

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you understand what the information is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that may not be clear to you. Make sure that you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

Professional Participant Information Sheet-Interviews

What is this Study about?

My name is Allison Campbell and I am a PhD student completing a research project at Ulster University in Coleraine. I would like to learn more about the experiences of young people/young adults who are providing care, assistance or support for a family member with a health condition in Northern Ireland, I am particularly interested on the impact this caring role has upon their education. The title of my research is 'The educational impact of being a young carer aged 16-24 years old in Northern Ireland'.

Why have I been chosen?

You have been invited to participate in this study because you have experience of working with young people aged 16-24 years old in Northern Ireland who provide care for a family member with a chronic health condition, physical disability, learning disability, mental ill health, alcohol/drug misuse within the family home.

Do I have to take part?

Your participation in this study is voluntary- it is up to you whether or not you take part. If you decide to take part, you will be asked to sign a consent form, if you do so, you can change your mind at any time and withdraw from the study without giving a reason.

What will happen to me if I take part?

If you consent, you will be asked to participate in an interview and will be asked to answer questions discussing your experiences of young carers, particularly in relation to their education. I am interested to learn about how their caring responsibilities may or may not have impacted on their education. This interview would last approximately one hour and if you consent an electronic voice recorder will be used to record this. This can take place at a time and location of your choice.

Are there any possible benefits to taking part?

By taking part in this study and sharing your experiences you have an opportunity to make a valuable contribution towards raising awareness and understanding about young carers and education in Northern Ireland. It is hoped that this research will

influence education policy to help young people with caring roles reach their potential and fulfil any educational aspirations they may have.

What my taking part in this study be kept confidential?

You will never be identified in the research findings by your real name as any reference to information provided by you will be anonymised. Any information that you give will be treated confidentially. The information that you give will be stored safely and securely and viewed only by the researcher and Supervisors. Once research is completed, in accordance with the Data Protection Act 1998, information will be securely stored for 10 years and then destroyed.

What will happen to the results of the study?

Results will be written up, analysed and contained in the researcher's PhD Thesis. Findings may also be published in academic journals. The final outcomes of this research will be available to any participant who requests it using the contact details below.

Who is organising and funding the research?

The researcher is funded by a DEL PhD Studentship meaning that the researcher's university fees are funded by the Department for Employment and Learning (DEL) and they receive a maintenance grant.

Who has reviewed this study?

This study has been reviewed by the researcher's Supervisors, the School of Education Ethics Filter Committee and the University Ethics Committee.

Who can I contact with questions about this study?

Thank you for taking the time to read this information sheet, should you have any questions or are unsure about any of the information provided please do not hesitate to get in touch.

You can contact me:

Allison Campbell

School of Education

Room 237

Ulster University

Coleraine

BT52 1SA

Email: Campbell-A62@email.ulster.ac.uk

I have two Supervisors for my research at Ulster University- Dr Una O'Connor Bones and Dr Jessica Bates. Any questions can be sent to my supervisors using the following contact information:

Dr Una O'Connor Bones

UNESCO Centre

School of Education

Ulster University

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Tel: 02870 324202

Email: ub.oconnor@ulster.ac.uk

Dr Jessica Bates

School of Education

Ulster University

Coleraine

BT52 1SA

Tel: 02870 124470

Email: j.bates@ulster.ac.uk



School of Education
Young Carers
and Education in
Northern Ireland
Interview Consent Form for Professionals

“The Educational Impact of being a Young Carer aged 16-24 years old in Northern Ireland”

Please tick

I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way. ☐

I understand that the researchers' will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers' to hold relevant personal data for the period prescribed by the university. ☐

I agree to take part in the above study ☐

I agree for the interview to be recorded on a voice recorder ☐

Name of Participant

Signature

Date

Name of Chief Investigator

Signature

Date

Name of Researcher

Signature

Date

Appendix Five – Information sheets and consent/assent forms for young carer interviewees, their parent/guardian and person receiving care



Young Carers School of Education and Education in Northern Ireland

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you understand what the information is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that may not be clear to you. Make sure that you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

Interview Participant Information

What is the purpose of the study?

My name is Allison Campbell and I am a PhD student completing a research project at Ulster University in Coleraine. I would like to learn more about the experiences of young people/young adults who are providing care, assistance or support for a family member with a health condition in Northern Ireland, I am particularly interested on the impact this caring role has upon your education. The title of my research is 'The educational impact of being a young carer aged 16-24 years old in Northern Ireland'.

Why have I been chosen?

You have been invited to participate in this study because you are aged between 16-24 years old, living in Northern Ireland and providing care to a family member with a chronic health condition, physical disability, learning disability, mental ill health, alcohol/drug misuse within your family home.

Do I have to take part?

Your participation in this study is voluntary- it is up to you whether or not you take part. If you decide to take part, you will be asked to sign a consent form, if you do so, you can change your mind at any time and withdraw from the study without giving a reason.

What will happen to me if I take part?

If you take part, you will be asked to participate in an interview and will be asked to answer questions discussing your experiences of your caring role and your education. You will be asked about the nature of the healthcare problem(s) of the person you provide care to. I am interested to learn about how caring may or may not have impacted on your education experience. This interview would last approximately one hour and if you consent an electronic voice recorder will be used to record this. This can take place at a time and location of your choice.

Are there any possible benefits to taking part?

By taking part in this study and sharing your experiences you have an opportunity to make a valuable contribution towards raising awareness and understanding about young carers and education in Northern Ireland. This could potentially influence education policy which could help other young people with caring roles reach their potential and fulfil any educational aspirations they may have.

Will my taking part in this study be kept confidential?

You will never be identified in the research findings by your real name as any reference to information provided by you will be anonymised. Any information that you give will be treated confidentially except as required by law or should you tell me something that could be harmful to you or others when I would have to report this to my Supervisors. The information that you give will be stored safely and securely and viewed only by the researcher and Supervisors. Once research is completed, in accordance with the Data Protection Act 1998, information will be securely stored for 10 years and then destroyed.

What will happen to the results of the study?

Results will be written up, analysed and contained in the researcher's PhD Thesis. Findings may also be published in academic journals. The final outcomes of this research will be available to any participant who requests it using the contact details below.

Who is organising and funding the research?

The researcher is funded by a DEL PhD Studentship meaning that the researcher's university fees are funded by the Department for Employment and Learning (DEL) and they receive a maintenance grant.

Who has reviewed this study?

This study has been reviewed by the researcher's Supervisors, the School of Education Ethics Filter Committee and the University Ethics Committee.

Who can I contact with questions about this study?

Thank you for taking the time to read this information sheet, should you have any questions or are unsure about any of the information provided please do not hesitate to get in touch.

You can contact me:

Allison Campbell

School of Education

Room 237

Ulster University

Coleraine

BT52 1SA

Email: Campbell-A62@ulster.ac.uk

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Tel: 02870 124470

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School of Education ~~Young Carers~~ and Education in Northern Ireland

Parent/Guardian and Family Member Information Sheet-Interviews

Your child/ children/relative have been invited to take part in a research study. This sheet is designed to give you information on what this research is for and what your child/children/relative will be asked to do. Please do not hesitate to ask any questions you may have about anything that may not be clear to you. Thank you for taking the time to consider this invitation.

What is the purpose of the study?

My name is Allison Campbell and I am a PhD student completing a research project at Ulster University in Coleraine. I would like to learn more about the experiences of young people/young adults who are providing care, assistance or support for a family member with a health condition in Northern Ireland, I am particularly interested on the impact this caring role has upon their education. The title of my research is 'The educational impact of being a young carer aged 16-24 years old in Northern Ireland'.

Why have/has my child/children/relative been chosen?

Your child/children/relative have been invited to participate in this study because they are aged between 16-24 years old, living in Northern Ireland and providing care to a family member with a chronic health condition, physical disability, learning disability, mental ill health, alcohol/drug misuse within the family home.

Your child/children/relative may have indicated that they wish to be interviewed on a Questionnaire that was also administered as part of this research.

Do they have to take part?

Your child/children's/relative's participation in this study is voluntary. If you wish your child/children/relative to take part, you will be asked to sign a consent form, if you do so, you can still change your mind at any time and withdraw from the study without giving a reason. Your child/children/relative will also be asked to give their consent to participate.

What will happen if my child/children/relative take part?

If your child/children/relative take part, they will be asked to participate in an interview and will be asked to answer questions discussing their experiences of their caring role and their education. Your child/children/relative will be asked about the nature of the healthcare problem(s) of the person they provide care to. I am interested to learn about how caring may or may not have impacted on their education experience. Your child/children/relative can refuse to answer any question or to stop the recorder and/ or the interview at any time. This interview would last approximately one hour and if you consent an electronic voice recorder will be used to record this. This can take place at a time and location of you and your child/children's choice.

Are there any possible benefits to taking part?

By taking part in this study and sharing their experiences they have an opportunity to make a valuable contribution towards raising awareness and understanding about young carers and education in Northern Ireland. This could potentially influence education policy which could help other young people with caring roles reach their potential and fulfil any educational aspirations they may have.

Will my child/children/relative taking part in this study be kept confidential?

Your child/children/relative will never be identified in the research findings by their real name as any reference to information provided will be anonymised. Any information that is given will be treated confidentially except as required by law or should they tell me something that could be harmful to them or others when I would have to report this to my Supervisors. The information that they give will be stored safely and securely and viewed only by the researcher and Supervisors. Once research is completed, in accordance with the Data Protection Act 1998, information will be securely stored for 10 years and then destroyed.

What will happen to the results of the study?

Results will be written up, analysed and contained in the researcher's PhD Thesis. Findings may also be published in academic journals. The final outcomes of this research will be available to anyone who requests it using the contact details below.

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BT52 1SA

Tel: 02870 124470

Email: j.bates@ulster.ac.uk



**School of Education
Young Carers
and Education in
Northern Ireland
Interview Assent Form**

To be completed by participant aged under 18 years old.

“The Educational Impact of being a Young Carer aged 16-24 years old in Northern Ireland”

You have been invited to take part in an interview for research being carried out to learn more about the educational experience of young people in Northern Ireland who have a caring role for someone at home.

You have been asked to take part because you are aged between 16-24 years old, live in Northern Ireland and provide care to a family member with a health condition.

By signing this form you are agreeing that:

- You want to take part in this research and be interviewed.
- You know that taking part is up to you and that you can change your mind later no questions asked.
- You know that your name will not be used alongside any results.
- You have read the information sheet that you have been given, have understood it and have been able to ask any questions that you had.
- You agree for the interview to be recorded on a voice recorder and if you are uncomfortable with this you agree to notes being taken.

Name of Participant

Signature

Date

(Printed)

Name of Researcher

Signature

Date

(Printed)



School of Education
Young Carers
and Education in
Northern Ireland
Interview Consent Form

To be completed by young person aged 18 years old and over

“The Educational Impact of being a Young Carer aged 16-24 years old in Northern Ireland”

Please tick

I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way. ☐

I understand that the researchers' will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers' to hold relevant personal data for the period prescribed by the university. ☐

I agree to take part in the above study ☐

I agree for the interview to be recorded on a voice recorder

□

Name of Participant

Signature

Date

Name of Chief Investigator

Signature

Date

Name of Researcher

Signature

Date



School of Education

**Young Carers
and Education in
Northern Ireland**

“The Educational Impact of being a Young Carer aged 16-24 years old in Northern Ireland”

Family Member Consent Form

To be completed by family member receiving care (if aged 18 and over) of interview participant aged 18 years old and over

Please tick

I confirm that I have been given and have read and understood the information

sheet for the above study and have asked and received answers to any questions raised.

☐

I understand that my relative's participation is voluntary and that they are free to withdraw at any time without giving a reason and without my rights being affected in any way.

☐

I understand that the researchers' will hold all information and data collected securely and

in confidence and that all efforts will be made to ensure that my relative cannot be identified as a participant in the study (except as might be required by law) and I give permission for

the researchers' to hold relevant personal data for the period prescribed by the university.

☐

I agree for my relative to take part in the above study.

☐

Name of Family Member	Signature	Date
Receiving Care (If over 18 years old)		

Name of Chief Investigator	Signature	Date
----------------------------	-----------	------

Name of Researcher	Signature	Date
--------------------	-----------	------



**School of Education
Young Carers
and Education in
Northern Ireland**

“The Educational Impact of Being a Young Carer aged 16-24 years old in Northern Ireland”

Parent/Guardian and Family Member Interview Consent Form

To be completed by Parent/Guardian/family member receiving care of interview participant aged under 18 years old

Name of Young Person:

Address:

Date of Birth:

Contact Details for Parent/Guardian

Name:

Address:

Mobile Telephone Number:

Daytime Number:

Relationship to Young Person

Please tick

I confirm that I have been given and have read and understood the information

sheet for the above study and have asked and received answers to any questions raised.

☐

I understand that my son/daughter's/relative's participation is voluntary and that they are free to withdraw at any time without giving a reason and without my rights being affected in any way.

☐

I understand that the researchers' will hold all information and data collected securely and

in confidence and that all efforts will be made to ensure that my son/daughter/relative cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers' to hold relevant personal data for the period prescribed by the university.

☐

I agree for my son/daughter/relative to take part in the above study.

☐

I agree for the interview to be recorded on a voice recorder if my son/daughter consents.

□

Name of Parent/Guardian

Signature

Date

Name of Family Member

Signature

Date

Receiving Care (If over 18
years old)

Name of Chief Investigator

Signature

Date

Name of Researcher

Signature

Date

Appendix Six – Ethical Approval Documents



Ulster University
 51-55 Foss
 Coleraine City
 County Antrim
 BT52 6PU
 Northern Ireland
 Tel: +44 (0)28 9036 6629
 ulster.ac.uk

Our Ref: NC:GOV

28 August 2017

Dr U O'Connor-Bones
 Room G235B
 School of Education
 Ulster University
 Coleraine Campus

Dear Dr O'Connor-Bones

Research Ethics Committee Application Number: REC/17/0011

Study Title: The educational impact of being a young carer aged 16-24 years old in Northern Ireland

Thank you for your recent response to matters raised by the committee. This has been considered and the decision of the committee is that the research should proceed.

Please also note the additional documentation relating to research governance and indemnity matters, including the requirements placed upon you as Chief Investigator.

The committee's decision is valid for a period of three years from today's date (this means that the study should be completed by that date). If you require this period to be extended, please contact the Research Governance section.

1. Please complete and return the Chief Investigator Statement of Compliance prior to commencing the study and keep a copy for your file.
2. Please retain all other documents.

Further details of the University's policy along with guidance notes, procedures, terms of reference and forms are available on the Ulster University Portal.

If you need any further information or clarification of any points, please do not hesitate to contact me.

Yours sincerely

Nick Curry
 Head of Research Governance
 028 9036 6629
n.curry@ulster.ac.uk



Ulster University,
 Stranmillis Road,
 Newtownabbey,
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ULSTER UNIVERSITY

RESEARCH GOVERNANCE

Project Reference Number: REC/17/0011

Project Title: The educational impact of being a young carer aged 16-24 years old in Northern Ireland

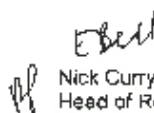
Statement on indemnity for staff and students conducting research on human participants

The University is indemnified, through its insurance policies (and subject to the terms and conditions of these policies), for its staff and students engaged in the pursuit of research involving human participants where the research is being conducted for and on behalf, and with the prior knowledge and consent of, the University.

However, the University is not indemnified through its insurance for non-negligent harm. Legal liability does not arise where a person suffers harm but no-one has acted negligently. The University cannot offer advance indemnities or, generally, insure against non-negligent harm, although such indemnity can be applied for in specific cases and where it is considered to be an essential element of the study.

Participants in research studies (research subjects) should be made aware in the Information provided to them of the University's position.

This statement is only valid if it is on headed paper, is signed and bears the Research Governance stamp.


 Nick Curry
 Head of Research Governance

DATE: 28 August 2017



KS

Kate Sewel

08/01/2018



RE: Barnardo's Research Ethics Committee (BREC) Response - Young Carers, NI

Thanks Allison – Happy to confirm that this research meets Barnardo's ethical research requirements, please liaise with the service to take the work forward, but please don't hesitate to get in touch if you have any further queries.

Good luck with the research!

Thanks
Kate



Incredible things happen when you believe in children

Appendix Seven – Stress Protocol

Great care has been taken to formulate questions that are as sensitive as possible to participants' personal situations. However, should a participant become distressed while discussing their caring role and education the following steps will be taken:

- Interviews will be stopped immediately.
- The young person's gateway organisation will be brought in to offer support.
- This will be followed up by the young person being directed towards other counselling and support services for further support should they feel they require it, for example Childline, Lifeline, their G.P.
- Organisations will be aware of this protocol before interviews are carried out.
- The Chief Investigator and additional investigator will be informed should these steps need to be implemented.

